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ABSTRACT

This curriculum is designed for a high school course in which nondisabled students receive training and act as peer tutors and role models for peers with special needs for one class period each day. An introductory course description covers peer tutor qualifications and requirements, examples of activities with peers, and benefits to peer tutors. A section on the tutor's role offers guidelines on motivation, the tutorial relationship, techniques of tutoring, setting goals, and suggestions for getting to know the tutee. The next section offers ideas and an activity for training peer tutors. A section of course-related forms includes tutor schedule forms, the record of tutor experiences, tutor evaluation forms, and observation schedules. The following section introduces special education services and covers such topics as current trends, legislation, definitions of key terms, discipline, and misconceptions about individuals with disabilities. The subsequent six sections each address a specific disability area with a variety of materials which include a general information fact sheet, a list of common misconceptions, a sample case study, and relevant article reprints. The six disabilities include: (1) mental retardation, (2) learning disabilities, (3) visual impairments, (4) hearing impairments, (5) speech and language disorders, and (6) autism. (Contains a total of 70 references.) (DB)

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ED 396 464

PEER TUTOR HANDBOOK

A Curriculum for High School Students Serving as Peer Tutors to Students with Special Needs

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TUTOR HANDBOOK

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II. The Tutor's Role

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X. Speech and Language Disorders

XI. Autism

References*

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Also included in the handbooks are fact sheets with the following information: General Information About Specific Disabilities, from the National Information Center for Children and Youth with Disabilities; Autism from the Autism Society of America; and Common Misconceptions about Autism from W. Stone, Ph.D.

* These references were used for developing the curriculum for the Peer Tutoring Handbooks.

I. Course Description

- Peer Tutoring Course Description
- Special Education Class Description

Peer Tutoring

Course Description: course # SST5800Y(F)(S)

This course is designed to enable students to develop peer relationships while acting as peer tutors and p[illegible]ve role models for students with special needs at McGavock High School. The tutors will receive instruction a[illegible]various types of disabilities and learning problems, instructional techniques for students with disabilities, and ideas on how to help increase the social skills, interactions, and participation of their peers with special needs in the day to day activities at McGavock High School and beyond.

Qualifications:

Students must have:

- an interest in the peer tutoring program
- an adequate GPA
- good attendance
- grade levels 9-12
- a recommendation from a teacher or counselor

To be taken as an elective:
1/2 credit per semester
1 class period per day

Requirements:

Students acting as peer tutors will report daily to an assigned teacher of one of the self-contained classes for students with disabilities. The peer tutor, teacher, and tutee will discuss and decide on an activity in which the tutor and tutee will participate. The tutor will be required to keep a daily or weekly journal, complete a weekly written assignment, and complete several reading assignments.

Examples of activities for the peers:

- visiting the library to read the paper, magazines, or other books - working on library skills, basic reading skills, and social integration and interaction
- eating lunch together - working on table manners, eating skills, social integration and interaction
- academics in the classroom - working on math, reading, or money skills, social interaction, listening skills, writing skills, conversational skills

Peer tutors may benefit from this program in the following ways:

- they may develop teaching and study skills
- they will practice academic and social skills
- they become advocates and learn valuable advocacy skills
- they are provided with realistic career exploration for education or human service profession, and
- they gain an impressive extracurricular activity for college applications or resumes

General program information:

This program has been approved by the Tennessee Department of Education. McGavock High School will be the first Metro school to participate in the peer tutoring program. The program is designed as a step towards the inclusion and integration of all students into the regular day to day activities of McGavock High School.

[illegible]cipating Faculty: Cheryl Gentry, Bryan Campbell, & Marilee Dye

Team Leader: Gladys Henderson

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SPECIAL EDUCATION CLASS DESCRIPTIONS

Ms. Henderson's Class:	The students in Ms. Henderson's class are working on a variety of skills including, academic, vocational and social skills. All of the students have good communication skills. Some of the students in Ms. Henderson's class take classes outside of her class or are mainstreamed. Many of her students have jobs outside of school.
Ms. Dye's Class:	The students in Ms. Dye's class work on vocational, academic and social skills. The students in her class have good communication skills and also take classes in the mainstream.
Ms. Gentry's Class:	The students in Ms. Gentry's class are not as "high functioning" as in Ms. Henderson's and Ms. Dye's classes. The skills that the students in her class focus on are vocational and social. some of the students in her classroom communicate using sign language and by other non-traditional means.
Mr. Campbell's Class:	The students in Mr. Campbell's class have Autism. The skills that they work on include, social skills, communication skills, and some academic skills. The students in this class use non-traditional means of communication.

II. The Tutor's Role

- Excerpts from the Governor's Study Partner Program from the Tennessee Department of Education

THE GOVERNOR'S STUDY PARTNER PROGRAM

• TUTOR'S MANUAL •

South Central Bell
A *BELLSOUTH* Company

Tennessee State Department of Education

How to

Introduction

The students being tutored in this program often feel locked out of the learning process. One reason for this feeling is not knowing how to tackle an assignment. Good study habits are the most important key to learning.

On the following pages you will find suggestions and examples for developing study skills. These suggestions are not to preach or teach; most of your study partners have heard it all before. They have not, however, learned or practiced good study habits. Using these skills as you work together may be your biggest contribution to your study partner's increased success in school.

Leaning is an active process. We learn through watching, listening, thinking, reading, practicing and doing. Your positive attitude and positive behavior will be more important than anything you can say. You cannot study for your partner, but you can guide the studying process and set an example.

Good News! Your study skills might be strengthened, too.

Tutor Tip

Beware! Doing homework is not necessarily the same as studying. Tips for getting the most out of homework are included in this section, but your goals are bigger than that. Spending your tutoring time on completing homework alone would be like choosing to eat one doughnut instead of owning the bakery.

MOTIVATION

The M work is a major reason for success in school and later in life. The lack of it is a major reason for failure. Many tutors have reported this to me with great alarm - "my study partner doesn't care." Several things should be said at this point. Some tutor tips:

✎ I don't care often is a cover-up for I don't know how. Struggling students get further and further behind until they reach a point that they do not know the question to ask - - much less the answer. They act as if I don't care.

✎ Motivation is caught more than it is taught. Your motivation may rub off. Your study partner's interest in school work may be increased because of your interest in him as a person.

✎ Relationships have a lot to do with our own reason to be motivated. Think briefly about your own school experience. What teachers are you most anxious to please? When do your put extra effort into your work? In what classes do you care more about your performance? How much did your answers have something to do with your relationship with your teachers? Probably a lot!

✎ Goals also play a big part in motivation. They keep us on track - going in a certain direction. Your study partner may have very few if any goals. Thus, he or she may have little or no direction and motivation - more about this when we talk about goal setting.

✎ The M work is greatly connected to ones interest. We actually work harder in areas we like. While I am highly motivated about football, driving many hours to see a game, I would not walk across the street to see a hockey match - but many would! Find areas of interest that your study partner may have. If there is motivation in one area - there is hope for motivation in another. I could learn to be motivated about hockey. A previous tip may also apply - I don't know may be a reason I don't care about hockey.

The Relationship

The R word is the key to being a successful tutor. It requires work, sweat and even on occasion tears. This is the reason the G.S.P.P. requires a one on one tutorial relationship. If "Sam" has a different tutor each time they meet it is very difficult for any "bonding" to take place. "Sam" needs more than a tutorial pool - he needs one individual with whom he can become a friend.

The Tutorial Rule

Be a friend first, tutor second and never the teacher.

Tips for the relationship

✎ Get to know Sam. Find out his interest/likes, dislikes/hobbies. Use the interest inventory to get you thinking. It is not designed for you to hand out to Sam saying "Fill this out, I'll be back to get it in 10 minutes."

✎ Keep in contact with Sam - This is not tutorial time - but in the hall, at lunch, or on the bus. If Sam says, "I can't come to our study this time, Aunt Matilda fell out of a barn over at Bucksnort and broke her big toe. We have to go see her." What should you say when you see Sam again? (Answer - "How's Aunt Matilda's toe?")

✎ Be patient with Sam - Your study partner may not - most likely - react as quickly as you do. Learning may not be as easy for Sam. His learning may be distracted due to other problems in his life. This will require work on your part unless you are one of the lucky ones born with a lot of it. It will be worth the effort - your character may be strengthened.

✎ Be positive with Sam - Show him what is right with his work - How can you say - you've got this wrong without saying you've got it wrong? "Let's do it again" is a good statement. Show progress that is being made - praise when success happens. Sam has had enough negatives. Positive reinforcement will help your study partner to "feel good" - I can will lead to I DID! Beware that the negative also works - I can fail may lead to I DID FAIL!

✎ Always exhibit a caring attitude! I care about you: I want you to do better in school. Remember the vehicle that carries what you know to your study partner is a caring spirit. **YOUR STUDY PARTNER NEEDS TO KNOW YOU CARE** before they will care about what you know. Your success as a tutor is not dependent upon how much you know, but rather how much you care.

TECHNIQUES OF TUTORING

- **BE POSITIVE-NOT NEGATIVE.** Place yourself in your study partner's situation. Sincere compliments always work better than embarrassing criticism. Drop "no" from your vocabulary.

- **BE COURTEOUS AND THOUGHTFUL.** This includes starting and stopping a lesson on time and being attentive to your study partner's conversation about himself and his personal problems. If you're willing to listen, you'll be amazed at how much he can teach you.

- **USE HUMOR TO MAKE THE SESSION FUN.** Never hesitate to admit a mistake or that you don't know something. It can be a great learning situation together.

- **BE PATIENT.** We all require understanding from others, and learning can be difficult when other problems in our lives also demand attention.

- **UNDERSTAND** that every learner has a lot of experience, information and knowledge even though his formal education may not have been adequate.

- You will often be the one who provides the encouragement to continue. **DISCUSS THE PROGRESS YOU HAVE MADE**, and write down what has been learned. It helps your study partner see his progress toward his goal.

- **BE FLEXIBLE.** Never think that because you've started one method that changes cannot be made. Think about the way your study partner learns best. Maybe he needs information now that you planned for later. Maybe he needs more of a challenge or a different approach. Remember that people learn differently. It's helpful when writing, listening and reading are all used, but it's up to you to find out what does succeed.

- **MAKE SURE** every lesson not only contains challenging work for your study partner but also contains enjoyable material that can be successfully handled.

- **YOUR STUDY PARTNER SHOULD UNDERSTAND WHAT HE IS TO DO.** It is easy to say too much, so say enough to be clear, then provide time for questions. Let him practice with the material before working on his own. Writing down the assignment helps.

- **LET HIM PARTICIPATE, NOT JUST LISTEN.** Having him correct his own papers will help him learn what needs to be worked on.

- **YOU ARE GUIDING YOUR STUDY PARTNER INTO INDEPENDENT LEARNING.** Everything you do should lead to that. Be glad when he tells you that something isn't working. That can mean he is analyzing some of his own learning needs.

- **REVIEW FOR RETENTION.** Practice is good, but don't do so much of it that it becomes unthinking behavior just to finish a page. However, allow for enough practice to learn the skill.

- **ALWAYS BE ALERT** to any problems needing special attention, such as hearing or visual difficulties.

INTEREST INVENTORY

NAME: _____

1. The things I like to do after school are:

2. The television programs I enjoy most are:

3. My hobbies are:

4. If I could take a trip, I would like to go to:

5. My favorite real-life hero is:

6. My favorite make-believe hero is:

7. The school subjects I like best are:

8. I like to read these types of stories:

SPORTS: Circle the sports you enjoy doing.

baseball	fishing	ice skating	swimming
basketball	football	jogging	tennis
bicycling	golf	roller skating	wrestling
bowling	handball	skateboarding	volleyball
boxing	hockey	soccer	other _____

INTERESTS: Check things you would like to know more about.

art	detectives	mystery	television
auto mechanics	electricity	race cars	woodwork
basketball	famous people	riddles	other _____
comic books	football players	rock stars	
cowboys	music	stories about people	

Getting To Know You

Use these questions to get to know your study partner better!

- Where were you born?
- How many are in your family?
- What do you do in your spare time?
- What kind of work do you do?
- Why did you take this course?
- What would you most like to gain from this course?
- What are four accomplishments that you are proud of?
- What is your favorite TV program?
- What were the best and worst things that happened to you last year?
- If you could change just one thing about this world, what would it be?
- What has been your most embarrassing moment?
- What is your favorite color and why?
- What makes you angry?
- Who is your favorite person?
- If you could trade places with someone, who would it be?

I Am . . .

- These things make me feel important, for example: making a good grade or getting a compliment.

- My favorite hobby is:

- I am good at (my best talent or skill is):

- My favorite school subject is:

- One of the most difficult things I have ever done is:

- I feel cared about or appreciated when:

I AM GOOD,
BUT I AM ALSO GETTING BETTER!

KNOW WHERE YOU WANT TO GO

Setting Goals

Goal setting should be an ongoing process **guided** by the tutor. As one goal is achieved it should be replaced by another goal. The study partner and the tutor should make their goals achievable. A reminder: The goals should be set by the study partner, who may have somewhat different goals from those the tutor might set. These points should be considered when setting realistic goals:

- Goals must be realistic - This is **very** important because the purpose of goal setting is for Sam to reach one. Setting a goal and reaching it is success. There are some things your S.P. can do that are not related (but they really are) to A B or C. Sam can:
    a. Come to class every day next week
    b. Come to class on time
    c. Come to class with his stuff - paper, pencil, book and assignment
    d. Do his homework on time

- Goals must be of short duration - Shorter the better. If the goal is realistic - Sam should reach it. (How can we know what Sam can do - remember previous tutor tips.) Success produces success. Praise your S.P. and then set another goal.

Setting and reaching of goals can be a very effective tool in the breaking of the cycle of failure. Nothing succeeds like success!

Don't Quit

When things go wrong, as they sometimes will,
When the road you're trudging seems all uphill,
When the funds are low and the debts are high,
And you want to smile, but you have to sigh,
When care is pressing you down a bit ~
Rest if you must, but don't you quit.

Life is unstable with its twists and turns,
As every one of us sometimes learns,
And many a person turns about
When they might have won had they stuck it out.
Don't give up though the pace seems slow ~
You may succeed with another blow

Often the struggler has given up
When he might have captured the victor's cup;
And he learned too late when the night came down,
How close he was to the golden crown.
Success is failure turned inside out ~
The silver tint of the clouds of doubt ~
So stick to the fight when you're hardest hit ~
It's when things seem worst that you mustn't quit.

III. Sample Activities and Lesson Plans

- Peer Tutor Training Ideas
- Sample Activity

PEER TUTOR TRAINING IDEAS

1. Peer tutor comes to SE classroom for the designated period for the first few days (1-5 days).

   A. Teacher talks about specific disability (characteristics of learning and behavior, specific to the designated student).

   B. Tutors move about room and choose a first and second choice for a partner to work with, or a Tutee may be chosen for them.

   C. Tutor and Tutee meet each other (with teacher prompts if necessary).

   D. Tutor and Tutee engage in a desired activity together in order to get acquainted. This is a good chance to observe behaviors.

2. Teachers train tutors (1-3 days).

   A. Tutors role (commitment, what is expected of them, etc.).

   B. Tasks and materials (Identify skills the tutees need to work on and ways the teacher addresses these skills).

   C. Appropriate means of giving directions, reinforcing, addressing inappropriate behaviors and giving feedback.

   D. Teacher individualizes instruction for each tutee. Skills and subject areas that need to be worked on. The tutor then picks the areas that they are interested in presenting to the tutee. Once the activities are discussed, the teacher helps the tutor evaluate what tutee's skillful in terms of the chosen activity (i.e., telling time, coin recognition, using sentences, initiating conversation, etc.).

   E. Teacher then demonstrates the activity, the tutor practices, is observed and given feedback.

   F. Teacher and Tutor discuss opportunity for social activities and social skills training.

SAMPLE ACTIVITY

Coin recognition

Objective: The tutee will recognize a penny, nickel, dime and a quarter.

	Activity	Date Accomplished
1.	A group of coins is placed on the desk and the tutee is asked to give the tutor a specific coin.	_____
2.	The tutee looks at pictures of coins and identifies them.	_____
3.	The tutee uses work sheets to practice matching different coins.	_____
4.	Using a money folder, the tutee is able to put the same coin in the box that was placed in the pocket below the box.	_____
5.	Two coins are placed in front of the tutee, one coin up and one coin down. She is asked to match the fronts and the backs of the coins.	_____
6.	The tutor creates a game to help the tutee learn to recognize coins.	_____

IV. Evaluation Forms

- Tutor Schedule Forms
- Record of Tutor Experiences
- Tutor Evaluation Forms
- Peer Tutor Observation Schedules

PEER TUTOR INFORMATION FORM

Please complete the following questions:

Name: _____ Phone number: _____

Grade: _____ School: _____

Free Period: _____ Lunch Period: _____

Are you available during lunch or after school? _____

Guidance Counselor: _____

Please list a teacher who can be contacted as a reference

Teacher's name: _____

Class they teach: _____

The students in the Life Skills classes have varying abilities and special needs. Please indicate which individual you are most interested in working with by numbering 1-4, 1 being the most interested and 4 being the least interested.

_____ Students who have higher skills

_____ Students with autism

_____ Students with physical disabilities

_____ Students with difficulties communicating

DO NOT WRITE BELOW THIS LINE

_____

Teacher: _____ Tutor: _____

Scheduled First Meeting: _____

Taking course for semester or year: _____

Comments: _____

_____

_____

_____

PEER TUTOR/INFORMTN FRM

Do you have any experience with people with disabilities? Yes/No
If yes, please describe.

What are some of the reasons why you are interested in working with people with disabilities?

Please list any questions, concerns or comments you may have regarding the Peer Tutoring Class.

Peer Tutor Class Schedule Name:_____

Clubs:_____ Meeting time:_____

Fall

	Monday	Tuesday	Wednesday	Thursday	Friday
1					
2					
3					
4					
5					
6					
AS					
L					

PLEASE INCLUDE THE COURSE, TEACHER AND ROOM NUMBER (IF POSSIBLE)

SPRING

	Monday	Tuesday	Wednesday	Thursday	Friday
1					
2					
3					
4					
5					
6					
AS					
L					

PLEASE INCLUDE THE COURSE, TEACHER AND ROOM NUMBER

Record of Tutor Experiences

As part of the course requirements, you are expected to complete a daily journal regarding your tutoring experience.

Completing Your Log:

In your daily log you may want to include your feelings, what you did with your tutee, behavioral observations of your tutee, what you enjoyed, what you did not enjoy or any other important or relevant information.

Sample:

Date: 1/10/94
Activity: Went to the library
Reflections: Today, Sarah and I went to the library to check out books. It took us a while to get there because Sarah kept stopping and talking to people in the hallway. Sarah seemed to enjoy being in the library looking at the magazines. She smiled and laughed while we looked through them. I am starting to feel more comfortable with Sarah and had a fun day today.

RECORD OF TUTOR EXPERIENCES

Tutor_____ Study Partner_____

A daily record of your hours, activities, and reflections of experiences.

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

Date:_____

Activity:_____

Reflections:_____

_____

_____

_____

TUTOR EVALUATION FORM

Teacher Name:_____ Date:_____

Tutor Name:_____ Tutee:_____

A. Peer Tutor is:	Always	Often	Sometimes	Seldom	Never
1. Dependable	5	4	3	2	1
2. Shows positive attitude	5	4	3	2	1
3. Uses reinforcement effectively	5	4	3	2	1
4. Helpful	5	4	3	2	1
B. Peer Tutor:					
1. Starts on time	5	4	3	2	1
2. Uses time wisely	5	4	3	2	1
3. Completes assignments	5	4	3	2	1
4. Has good rapport with tutee	5	4	3	2	1
5. Seeks help if needed	5	4	3	2	1

C. Successful activities and procedures:

D. Suggested activities and objectives:

E. Additional Comments:

_____ _____

Teacher Date

_____ _____

Tutor Date

Tutor Observation Schedule

Tutor	Interview Date	Observations Date/comments	Evaluation Date/Comments

V. Introduction to Special Education Services

- Current Trends in Special Education
- Special Education Legislation & Definitions
  - Least Restrictive Environment
  - Multidisciplinary Team
  - Individualized Education Program
- Disciplinary Procedures
- Misconceptions about Exceptional Children
- Misconceptions about Persons with Disabilities
- County Graduates Defy Odds to Realize Goals
- Issues in Special Education: An Act of Transformation
- Peer Group Education

Current Trends and Issues

Bob Dylan could have written his song "The Times They Are A-Changin'" for the field of special education. Special education has a rich history of controversy and change. In fact, controversy and change are what make the teaching and study of people with disabilities so challenging and exciting. The 1980's and 1990's have seen especially dramatic changes in the education of people with disabilities, and current thinking indicates that the field is poised for still more changes.

Integration

Integration, sometimes referred to as mainstreaming, involves the movement of people with disabilities from institutions to community living, from special schools to regular public schools, from special classes to regular classes. As a broadly supported social issue, integration began in the 1960's and is going stronger than ever today. In the 1960's and 1970's, champions of integration were proud of the fact that they were able to reduce the number of people with disabilities residing in institutions and the number of special education students attending special schools and special self-contained classes. Some of today's more radical proponents of integration, however, will not be satisfied until virtually all institutions, special schools, and special classes are eliminated. They propose that all students with disabilities be educated in regular classes. And even today's more conservative advocates of integration are recommending a much greater degree of interaction between students with and without disabilities that was ever dreamed of by most special educators in the 1960's and 1970's.

Normalization

A philosophical belief in special education that every individual, even the most disabled, should have an educational and living environment as close to normal as possible.

SPECIAL EDUCATION LEGISLATION AND DEFINITIONS

Two landmark federal laws were passed in 1990: the Individuals with Disabilities Education Act (IDEA) and Americans with Disabilities Act (ADA). IDEA amended a 1975 law and it ensures that all children and youth with disabilities have the right to a free appropriate public education. ADA ensures individuals to non discriminatory treatment in other aspects of life and provides civil rights protection in areas of employment, transportation, public accommodations, and telecommunications.

IDEA legislation mandates that special education services be provided. Special education services are provided at no cost to parents, are designed to meet the unique needs of the child, and are supervised and directed by public school personnel in a setting that meets state standards. This is called a FREE APPROPRIATE PUBLIC EDUCATION (FAPE).

WHAT?

SPECIAL EDUCATION SERVICES	RELATED SERVICES	INDIVIDUALIZED EDUCATION PROGRAM
Special Education services are specially designed instruction determined by the unique needs of the student and should be as nearly like the regular school program as possible. Special Education can take place in a variety of settings from the regular classroom to hospital or home instruction.	Related Services are provided to assist the student to benefit from special education. Related Services include, but are not limited to, the following: • Transportation • Hearing Services • Vision Services • Counseling Services • Physical Therapy • Occupational Therapy • Speech/Language Therapy	All services must be provided according to an individualized education program or IEP. An IEP is a written program developed by the parents and the school system personnel and includes: • The type of services • Long-term goals for the student • Short-term objectives or intermediate steps; not daily lesson plans • Other services, if needed

PLACEMENT MUST OCCUR IN THE LEAST RESTRICTIVE ENVIRONMENT

The special education and related services to be provided and the amount of participation in the regular education program is called PLACEMENT. Placement must be provided in the LEAST RESTRICTIVE ENVIRONMENT. The Least Restrictive Environment is determined by the amount of time an eligible child spends with children who do not have disabilities.

WHERE?

LEAST	RESTRICTIVE	ENVIRONMENT
Student should attend the school he/she would attend if not disabled. If this is not appropriate, the place where student goes to school should be as much like the regular school and as close to student's home as possible.	The place where student goes to school should not separate him/her from the regular school program or from peers of similar chronological age any more than necessary	Student's school program should be in a setting where he/she can be with non-disabled children as much as possible.

Decisions about the student's Individualized Education Program (IEP) in the least restrictive environment must be developed at a meeting of the MULTIDISCIPLINARY TEAM (M-TEAM).

WHO?

MULTIDISCIPLINARY TEAM

An M-Team is a group of people that mush include at least:

- the parent or legal guardian
- the student, when appropriate
- A teacher who knows about the instructional needs of the child
- The principal or someone that he/she assigns
- A specialist who understands and can explain the results of the student's assessment (this person is only required at the initial or first meeting)

The parent, or the school system may invite other persons to attend the M-Team meeting.

FOUR VERY IMPORTANT THINGS HAPPEN AT M-TEAM MEETINGS:

The members of the M-Team will do the following:

1. Determine if student is eligible for special education services at the time of the initial and re-evaluation (at least every three years),
2. Develop the individualized education program for the student,
3. Decide which special education services the student will receive, and
4. Decide if other services are essential to the educational program of the student.

THE INDIVIDUALIZED EDUCATION PROGRAM (IEP)

Contents of the IEP

When the M-Team meets to develop the IEP they will discuss the following components which will be included in the IEP:

(1) Student's present levels of performance;

(2) Annual goals expected to be achieved at the end of one year for area(s) of need;

(3) Short term objectives which measure progress toward meeting the goal(s);

(4) Specific educational and related services needed;

(5) A description of the amount of time, number of sessions, anticipated duration of the service, the date the service will begin and end, and who will be responsible for providing the service;

(6) The type of vocational services needed and, if they aren't needed, why such services aren't needed;

(7) A statement of the needed transition services for student beginning at age 16 (14 or younger, if needed) which will promote the understanding of and capability to make the transition from "student" to "adult";

(8) How much time the student will participate in regular education and in special education services provided in the regular classroom;

(9) State mandated tests which the child will take during the IEP period and, if appropriate, modifications to be made and

(10) Methods of monitoring the student's progress at least annually, and naming the person responsible for this monitoring.

After the M-Team has completed the IEP, the parent may request a copy of the IEP to take home.

NOTE: Some children with disabilities may need special equipment such as wheelchairs, braces, crutches or assistive technology devices/equipment. The school system must make arrangement, if required, in order for a child with a disability to attend and participate in school. Any necessary special arrangements should be included in the child's IEP.

DISCIPLINARY PROCEDURES

WHAT IS THE SCHOOL SYSTEM REQUIRED TO DO WHEN DISCIPLINING CHILDREN WITH DISABILITIES?

Appropriate behavior is expected of all children. A child who has a disability and exhibits inappropriate behavior may need to be disciplined. If misbehavior is a problem, the child's IEP should include goals directed toward improving the child's behavior.

If it is necessary to discipline an eligible child by excluding the child from school for a total of more than ten school days per school year, procedural safeguards must be followed. Since exclusion of an eligible child for more than a total of ten school days per school year is considered to be a change in educational placement, the M-Team must meet to make decisions regarding the student's behavior.

THE M-TEAM MUST DECIDE the following:

1. Was the behavior a result of the child's disability?

2. Are the current IEP and placement appropriate?

If the M-Team determines that the behavior was a result of the child's disability, the child cannot be excluded from an educational setting and must be placed in a setting that more appropriately meets the child's needs.

If the M-Team determines that the behavior was not a result of the child's disability, the student may be excluded from school, but educational services as determined by the M-Team, must be provided during that period. Services delivered to the eligible child must be based on the goals/objectives of the child's IEP and provided by a teacher who is endorsed in Special Education.

If the school system determines that a student should be removed from school for more than ten days per school year for dangerous or disruptive conduct, the system has the following options:

1. School system obtains a parent's consent, to exclude the child from school, or

2. If a parent does not consent, school officials must secure a federal court injunction to exclude your child.

If your mentee exhibits problem behavior that results in a school disciplinary process, it is important that you, as a mentor and advocate, are aware of the disciplinary procedures and due process.

Please see enclosed handouts for explicit definitions of code of student conduct and procedures.

MISCONCEPTIONS ABOUT EXCEPTIONAL CHILDREN

MYTH ➢ Public schools may choose not to provide education for some students.

FACT ➢ Federal legislation specifies that to receive federal funds, every school system must provide a free, appropriate education for every student regardless of any disabling condition.

MYTH ➢ By law, the student with a disability must be placed in the least restrictive environment (LRE). The LRE is always the regular classroom.

FACT ➢ The law does require the student with a disability to be placed in the LRE. However, the LRE is *not* always the regular classroom. What the LRE does mean is that the student shall be segregated as little as possible from home, family, community, and the regular class setting while appropriate education is provided. In many, but not all, instances this will mean placement in the regular classroom.

MYTH ➢ The causes of most disabilities are known, but little is known about how to help individuals overcome or compensate for their disabilities.

FACT ➢ In most cases, the causes of disabilities are not known, although progress is being made in pinpointing why many disabilities occur. More is known about the treatment of most disabilities than about their causes.

MYTH ➢ People with disabilities are just like everyone else.

FACT ➢ First, no two people are exactly alike. People with disabilities, just like everyone else, are unique individuals. Most of their abilities are much like those of the "average" person who is not considered to have a disability. Nevertheless, a disability is a characteristic not shared by most people. It is important that disabilities be recognized for what they are, but individuals with disabilities must be seen as having many abilities—other characteristics that they share with the majority of people.

MYTH ➢ A disability is a handicap.

FACT ➢ A disability is an inability to do something, the lack of a specific capacity. A handicap, on the other hand, is a disadvantage that is imposed on an individual. A disability may or may not be a handicap, depending on the circumstances. For example, inability to walk is not a handicap in learning to read, but it can be a handicap in getting into the stands at a ball game. Sometimes handicaps are needlessly imposed on people with disabilities. For example, a student who cannot write with a pen but can use a typewriter or word processor would be needlessly handicapped without such equipment.

MISCONCEPTIONS ABOUT PERSONS WITH DISABILITIES

MYTH ≻ Normalization, the philosophical principle that dictates that the means and ends of education for students with disabilities should be as culturally normative as possible, is a straightforward concept with little room for interpretation.	**FACT** ≻ There are many disagreements pertaining to the interpretation of the normalization principle. As just one example, some have interpreted it to mean that all people with disabilities must be educated in regular classes, whereas others maintain that a continuum of services (residential schools, special schools, special classes, resource rooms, regular classes) should remain as options.
MYTH ≻ All professionals agree that technology should be used to its fullest to aid people with disabilities.	**FACT** ≻ There are some who believe that technology should be used cautiously because it can lead people with disabilities to become too dependent on it. Some believe that people with disabilities can be tempted to rely on technology rather than develop their own abilities.
MYTH ≻ Research has established beyond a doubt that special classes are ineffective and that mainstreaming is effective.	**FACT** ≻ Research comparing special versus mainstream placement has been inconclusive because most of these studies have been methodologically flawed. Researchers are now focusing on finding ways of making mainstreaming work more effectively.
MYTH ≻ Professionals agree that labeling people with disabilities (e.g., retarded, blind, behavior disordered) is more harmful than helpful.	**FACT** ≻ Some professionals maintain that labels help professionals communicate, explain the atypical behavior of some people with disabilities to the public, and spotlight the special needs of people with disabilities for the general public.
MYTH ≻ People with disabilities are pleased with the way the media portrays people with disabilities, especially when they depict extraordinary achievements of such persons.	**FACT** ≻ Some disability rights advocates are disturbed with what they believe are too frequent overly negative *and* overly positive portrayals in the media.
MYTH ≻ Everyone agrees that teachers in early intervention programs need to assess parents as well as their children.	**FACT** ≻ Some authorities are now of the opinion that, although families are an important part of intervention programming and should be involved in some way, special educators should center their assessment efforts primarily on the child and not the parents.
MYTH ≻ Everyone agrees that good early childhood programming for students with disabilities should follow the same guidelines as that for nondisabled preschoolers.	**FACT** ≻ There is considerable disagreement about whether early intervention programming for children with disabilities should be child-directed, as is typical of regular preschool programs, or should be more teacher-directed.
MYTH ≻ Professionals agree that all students with disabilities in secondary school should be given a curriculum focused on vocational preparation.	**FACT** ≻ Professionals are in conflict over how much vocational versus academic instruction students with mild disabilities should receive.

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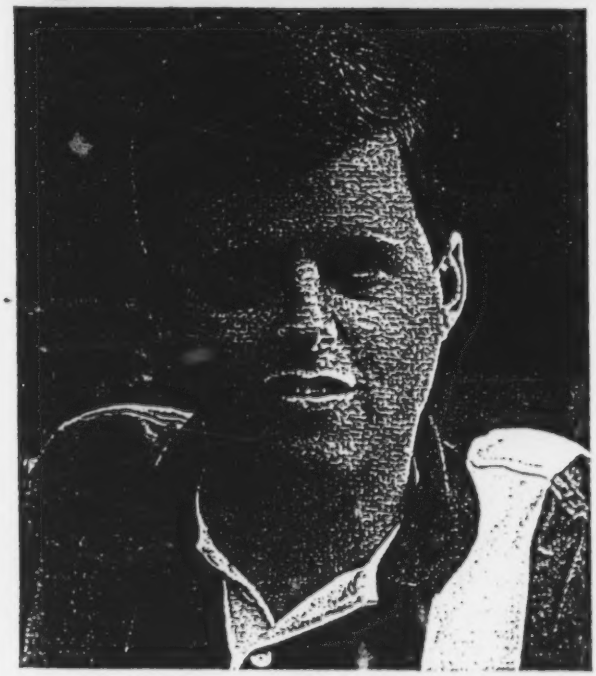
OUNTY GRADUATES DEFY ODDS TO REALIZE GOALS > by Tammy Poole



PROGRESS PHOTO BY MATT GENTRY

Tony Hensley says he'd like to study business administration in college.

With a 3.8 grade-point average, Hensley is in the top 10 percent of his class.

Young photographer focuses on attending a more accessible UVa

The University of Virginia should be more accessible to Tony Hensley in a couple of years.

The problem is not academic. Right now, parts of UVa's campus are not physically accessible for the Western Albemarle High School senior.

Hensley was born with a muscular condition that left him weak, and he started using a wheelchair after he was injured in an automobile wreck.

"I plan to attend Peidmont Virginia Community College for two years and transfer to UVa," he said. "With the Americans with Disabilities Act, it should be more accessible in a couple of years."

In 1986, nine months after having two metal rods placed in his back to help correct curvature of the spine, Hensley was injured in a car accident.

He was trapped in the vehicle for 45 minutes, and his leg was broken in three places.

Being the only senior at WAHS in a wheelchair has not hindered his progress in any way, Hensley said.

The school is accessible for people with disabilities, he said. And his disability is no big deal to his classmates. He said he gets treated the same as everyone else.

He and his 215 classmates graduate tonight at 8 p.m. in Warrior Stadium at the High School.

With a 3.8 grade-point average, Hensley is in the top 10 percent of his class. He is a member of the National Honor Society and the French Honor Society and has won various academic awards. Hensley loves photography and stays busy photographing weddings and other events. He also was hired to photograph several senior portraits this year.

He became interested in photography while on the yearbook staff at Heritage Christian School.

Hensley drives a van and often goes on the Blue Ridge Parkway to take photographs that he mats and sells.

He is not sure whether photography would be profitable enough to make a living. "I'm interested in business administration," he said. "Eventually I'd like to be a business owner of some sort."

Hensley lives in North Garden with his parents, John M. and Betty Jo Hensley.

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An Act of Transformation: Law for Disabled to Change Workplace

CNN

The most far-reaching civil rights law since the 1960s takes effect Sunday, promising to force the kind of wholesale changes that would make the American workplace far more hospitable to workers with physical and mental disabilities.

The new law, the second phase of the Americans With Disabilities Act, outlines changes that companies must make to nearly every facet of employment, from job applications and interviews, to health insurance plans, compensation and work schedules—all designed to extend to the disabled the same rights that women and minorities won nearly three decades ago.

At many companies in the Washington area and across the country, managers already are bending and flexing to meet the needs of disabled workers.

Marriott Corp. uses interpreters to help a hearing-impaired employee at its Bethesda headquarters understand what is being said at staff meetings. A blind manager at Nordstrom's Pentagon City store has a scanner attached to his computer that reproduces ordinary documents in Braille.

In Atlantic City, owners of the Trump Castle casino altered a blackjack table to help a dealer who uses a wheelchair. And Continental Insurance, a New York-based property and casualty company, has an enlarging device attached to a computer so that a clerical worker with poor vision can see her keyboard more clearly.

Since it affects all industries, and ultimately touches millions of businesses, the act has a scope matched by few other laws. Generally, it is being praised by businesses as an effort to reach out to a disenfranchised segment of society. But it also has drawn criticism from industry groups that fear it could open the floodgates to litigation and subject businesses to large financial judgments by juries . . . .

The law does not state precisely what a company must do or spend to ensure that it does not discriminate, since what is appropriate for a commercial giant like IBM might not be for a small retailer. What the law does require is that employers make "reasonable accommodations" to assure that qualified applicants with physical or mental disabilities are not discriminated against, unless the employer can show that the accommodation would put an "undue hardship" on its operations.

For a large law firm, that could mean providing a reader for a lawyer who is blind; for a computer company, it could mean widening doorways or adjusting a desk's height to accommodate a systems analyst in a wheelchair.

The law goes well beyond traditional notions of disability by including any person with an impairment that substantially limits a major life activity. It protects people with AIDS, with cosmetic disfigurements, with dyslexia, even those who suffer from stress or depression if their condition is so severe as to be considered disabling by a psychiatrist . . . . To prepare themselves for the July 26 deadline, companies in recent weeks have been doing everything from scrutinizing the wording of job applications to reviewing hiring and promotion practices to ensure nothing they do could be considered discriminatory.

Under the new law, for example, applicants cannot be asked whether they have a disability, only whether they are able to perform specific functions that are considered essential to a job. For employers, that often means determining just exactly what are the essential functions of each job.

"Is it essential for a painter in a wheelchair to be able to reach the ceiling? Probably not, if we have a crew of 30 other painters who can do it," said Roger Wagner, president of Trump Castle, which is reviewing some 600 distinct jobs to determine their essential functions . . . .

Even with the force of the act on their side, many advocates for the disabled say it will be some time before the fortunes of that community improve significantly. The unemployment rate among those with disabilities is estimated to run as high as 60 percent and, as a result, many lack the skills necessary to compete for jobs.

"It is a Catch-22," said Peter Blanck, a University of Iowa law professor who is involved in a study of persons with disabilities. "If you haven't been in the work force, you won't have the skills needed for a lot of jobs."

The act does not mandate job quotas; it only requires that employers hire and promote qualified candidates, whether they have a disability or not.

To Mary Beth Chambers, a deaf employee who works the cosmetics counter at Nordstrom's Pentagon City store, the struggle for equality in the work place is well worth it.

"It's not people's fault that they're hearing-impaired," said Chambers, who reads customers' lips.

"Companies don't know what they're missing," she said. "These people are capable of doing anything, and if they keep trying, their dreams will come true."

SOURCE: Liz Spayd, *The Washington Post*, Sunday, July 26, 1992, pp. C1, C9. © 1992, The Washington Post. Reprinted with permission.

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Peer-Group Education

Although the widening world of childhood contains hundreds of lessons delivered by parents and teachers, young people deliver powerful lessons to one another, too. Small children are uncanny about teaching each other "the ropes" to acceptable childhood living. For example, I recall seven-year-old Bob McGee, with mental retardation and cerebral palsy, who fell to the floor kicking and screaming every time a teacher tried to take off his bib. Then when the developmental center closed down and Bob was transferred to a special class in a regular public school, he had attended for only two days before the bib came off! It takes little imagination to know what probably went on between him and the other students.

Teen-agers perform rich informal functions in teaching one another what life is all about and how they want their generation to shape the world. Although this curriculum cannot be found in books, teen-agers share with each other their own . . .

values
clothing styles
meaningful slang words
sense of justice
choice of foods
hope for the future
even their anger for mistakes their elders made before them.
(Have you forgotten?)

Until recently, many children with handicaps were denied peer-group interactions with others their own age. Like victims of apartheid, they attended special schools, rode special buses, and participated in special recreation programs. Of course, such distinctive activities had value, and there always will be a need for some specialized programs. Nevertheless, such utter isolation produced tragic consequences. It placed one more barrier in their path to the richest life possible. Now this unfair obstacle is being lowered.

Today many preschools integrate children with developmental disabilities into classes with their "normal" peers. And what often goes on in such settings can enlighten us all. A documentary film, *Why Be Friends*, described integrated preschools in eastern Nebraska. "Normal" children spoke openly and in unrehearsed fashion about their friends with handicaps. One four-year-old was asked about her relationship with a friend having multiple handicaps.

"What's that thing behind Carrie's head?"

"That's the thing that holds her head."

"Why does she have to have that?"

"Because then her head won't do anything, but it helps her lean back a lot."

"How would you feel if Carrie couldn't come here to school?"

"Well, then I'd go to her house."

Experiences like these in integrated preschools teach us that prejudice against persons with handicaps is *learned* behavior. And if prejudice can be taught by what we elders say (or fail to say), then tolerance, respect, and love for those with disabilities can be taught, too.

Forward-thinking public schools recognize the power of peer-group education. Dr. Lou Brown from the University of Wisconsin, which has close training relationships with the Madison Metropolitan School District, gave a touching rationale for such involvements at one of the symposiums on the United Nations' International Year of the Child (1979). He felt that neighborhood children should relate to students with even severe and profound handicapping conditions.

> Children with severe and profound handicaps need to be in regular schools, too. This interaction between these handicapped students and other students is utterly remarkable. And why not? After all, the future parents of such handicapped children are in the schools today. And what kind of

attitudes, values and expectations will such parents need? Also, future doctors, teachers, lawyers, policemen and ministers are in the schools, too. They need to grow up with such children so they will understand them and not reject them. Therefore, we are making conscious and systematic attempts to make sure that every student has some kind of interaction with such handicapped people. And in some schools I work closely with, we train regular students to handle seizures in school . . . to work with handicapped students at recess, in the gym and the swimming pool . . . to hire out as baby sitters for handicapped children . . . to help some learn to ride the bus . . . to wheel students in wheelchairs to and from school. In many cases, regular students receive class credit for their involvements with handicapped persons. These students have become so attracted to one another, we can't keep them apart.[1]

Harold Howe II, the former United States Commissioner of Education and present vice president of Education and Research at the Ford Foundation, believes strongly that peer-group education will become a new way of life in public schools by A.D. 2024. He stated, "What the schools increasingly reward is not the student's own achievement but his contribution to the achievement of others. And the higher his own attainments in learning, the more he is expected to do in helping others to learn."[2]

It will happen. We can slow it down, however, as long as we keep people with handicaps apart from the rest of us.

Consider These Options

- Become interested in remarkable relationships between persons with handicaps and so-called normal persons in your neighborhood. They form the stuff books and speeches are made of. I make a living from such happenings—maybe you can observe relationships worth writing or talking about, too.

- Know that life becomes exciting and the world moves forward when people with individual differences understand and accept each other. After all, when we associate only with those who think like we do, act like we do, dress like we do, talk like we do—well, it can get downright boring.

- Watch your local public schools. Every time you see them develop a program that even smells like peer-group education involving persons with handicaps, reinforce them. Send written thank yous. Submit letters to editors. Thank the persons responsible personally. Even hug them and kiss them, if you can get away with it.

- Know that peer-group education is a coming way of life. It *is* coming. It is up to us to develop detailed responses that will help it along.

1. Robert Perske, ed., *The Child with Retardation—The Adult of Tomorrow: An International Year of the Child Report Sponsored by the International League of Societies for the Mentally Handicapped and the Association for Retarded Citizens* (Arlington, Tex.: ARC-National Headquarters, 1980).
2. Harold Howe, "Report to the President of the United States from the Chairman of the White House Conference on Education, August 1, 2024," *Saturday Review World* (August 24, 1974).

VI. Mental Retardation

- General Information about Mental Retardation (NICHCY Fact Sheet)

- Misconceptions about Persons with Mental Retardation

- The Importance of Friendship

- General Information about Down Syndrome (NICHCY Fact Sheet)

- Mainstreaming Case History: R.J. was Mentally Retarded

NICHCY

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General Information About

MENTAL RETARDATION

Definition

People with mental retardation are those who develop at a below average rate and experience difficulty in learning and social adjustment. The regulations for the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (Public Law 94-142), provide the following technical definition for mental retardation:

> "Mental retardation means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational performance."

"General intellectual functioning" typically is measured by an intelligence test. Persons with mental retardation usually score 70 or below on such tests. "Adaptive behavior" refers to a person's adjustment to everyday life. Difficulties may occur in learning, communication, social, academic, vocational, and independent living skills.

Mental retardation is not a disease nor should it be confused with mental illness. Children with mental retardation become adults; they do not remain "eternal children." They do learn, but slowly and with difficulty.

Probably the greatest number of children with mental retardation have chromosome abnormalities. Other biological factors include (but are not limited to): asphyxia (lack of oxygen); blood incompatibilities between the mother and fetus; and maternal infections, such as rubella or herpes. Certain drugs have also been linked to problems in fetal development.

Incidence

Some studies suggest that approximately 1% of the general population has mental retardation (when both intelligence and adaptive behavior measures are used). According to data reported to the U.S. Department of Education by the states, in the 1989-90 school year, 564,666 students ages 6-21 were classified as having mental retardation and were provided services by the public schools. This figure represents approximately 1.7% of the total school enrollment for that year. It does not include students reported as having multiple handicaps or those in non-categorical special education preschool programs who may also have mental retardation.

Characteristics

Many authorities agree that people with mental retardation develop in the same way as people without mental retardation, but at a slower rate. Others suggest that persons with mental retardation have difficulties in particular areas of basic thinking and learning such as attention, perception, or memory. Depending on the extent of the impairment—mild, moderate, severe, or profound—individuals with mental retardation will develop differently in academic, social, and vocational skills.

Educational Implications

Persons with mental retardation have the capacity to learn, to develop, and to grow. The great majority of these citizens can become productive and full participants in society.

Appropriate educational services that begin in infancy and continue throughout the developmental period and beyond will enable children with mental retardation to develop to their fullest potential.

As with all education, modifying instruction to meet individual needs is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

In teaching persons with mental retardation, it is important to:

- Use concrete materials that are interesting, age-appropriate, and relevant to the students;
- Present information and instructions in small, sequential steps and review each step frequently;
- Provide prompt and consistent feedback;
- Teach these children, whenever possible, in the same school they would attend if they did not have mental retardation;
- Teach tasks or skills that students will use frequently, in such a way that students can apply the tasks or skills in settings outside of school; and
- Remember that tasks that many people learn without instruction may need to be structured, or broken down into small steps or segments, with each step being carefully taught.

Children and adults with mental retardation need the same basic services that all people need for normal development. These include education, vocational preparation, health services, recreational opportunities, and many more. In addition, many persons with mental retardation need specialized services for special needs. Such services include diagnostic and evaluation centers; special early education opportunities, beginning with infant stimulation programs and continuing through preschool; and educational programs that include age-appropriate activities, functional academics, transition training, and opportunities for independent living and competitive employment to the maximum extent possible.

Resources

Smith, R. (Ed.). (1993). *Children with mental retardation: A parents' guide.* Rockville, MD: Woodbine House. [Telephone: 800-843-7323 (outside DC area); (301) 468-8800 (in DC area).]

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life.* Rockville, MD: Woodbine House. (See telephone number above.)

Organizations

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003

American Association on Mental Retardation (AAMR)
1719 Kalorama Road, N.W.
Washington, D.C. 20009
(202) 387-1968; (1-800) 424-3688 (Toll-Free)

National Down Syndrome Congress
1605 Chantilly Drive Suite 250
Atlanta, GA 30324
(400) 633-1555; (1-800) 232-6372 (Toll-Free)

National Down Syndrome Society
666 Broadway, Suite 810
New York, NY 10012
(212) 460-9330; (1-800) 221-4602 (Toll-Free)

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UPDATE 12/93

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MISCONCEPTIONS ABOUT PERSONS WITH MENTAL RETARDATION

MYTH ≻ Mental retardation is defined by how a person scores on an IQ test.	**FACT** ≻ The most commonly used definition specifies that, in order for a person to be considered mentally retarded, he or she must meet two criteria: (1) low intellectual functioning *and* (2) low adaptive skills.
MYTH ≻ Once diagnosed as mentally retarded, a person remains within this classification for life.	**FACT** ≻ A person's level of mental functioning does not necessarily remain stable, particularly for those who are mildly retarded. With intensive educational programming, some persons can improve to the point that they are no longer retarded.
MYTH ≻ In most cases, we can identify the cause of retardation.	**FACT** ≻ In most cases, especially of those who are mildly retarded or who require less intensive support, we cannot specify the cause. For many children who are mildly retarded, poor environment may be a causal factor, but it is extremely difficult to document.
MYTH ≻ Most mentally retarded children look different from nondisabled children.	**FACT** ≻ The majority of children with mental retardation are mildly retarded, or require less intensive support, and most of these look like nondisabled children.
MYTH ≻ We can identify most cases of mental retardation in infancy.	**FACT** ≻ Because most children with retardation are mildly retarded, because infant intelligence tests are not very reliable and valid, and because intellectual demands on the child increase greatly upon entrance to school, most children with retardation are not identified as retarded until they go to school.
MYTH ≻ Persons with mental retardation tend to be gentle people who have an easy time making friends.	**FACT** ≻ Because of a variety of behavioral characteristics and because they sometimes live and work in relatively isolated situations, some persons with mental retardation have difficulty making and holding friends.
MYTH ≻ The teaching of vocational skills to students with retardation is best reserved for secondary school and beyond.	**FACT** ≻ Many authorities now believe it appropriate to introduce vocational content in elementary school to students with mental retardation.
MYTH ≻ When workers with mental retardation fail on the job, it is usually because they do not have adequate job skills.	**FACT** ≻ When they fail on the job, it is more often because of poor job responsibility (poor attendance and lack of initiative) and social incompetence (interacting inappropriately with coworkers) than because of incompetence in task production.
MYTH ≻ Persons with mental retardation should not be expected to work in the competitive job market.	**FACT** ≻ More and more persons who are mentally retarded hold jobs in competitive employment. Many are helped through supportive employment situations in which a job coach helps them and their employer adapt to the work place.

THE IMPORTANCE OF FRIENDSHIP

Professionals often overlook the fundamental importance of friendship. The following extract highlights the critical role friendship can play in the lives of people who are mentally retarded.

> A sense of belonging, of feeling accepted and of having personal worth are qualities that friendship brings to a person. Friendship creates an alliance and a sense of security. It is a vital human connection.
>
> People who are mentally retarded want and need friendship like everyone else. Yet they typically have few opportunities to form relationships or to develop the skills necessary to interact socially with others. Their exposure to peers may be limited because they live and work in sheltered or isolated environments. They usually lack a history of socializing events like school clubs, parties, or sleepovers that help to develop or refine personal skills. They may not know how to give of themselves to other people and may be stuck in an egocentric perspective. Persons who are retarded may also respond inappropriately in social situations. Many people shun adults with retardation who freely hug or kiss strangers when greeting them . . . .
>
> Because of their few contacts and opportunities, persons with retardation may attempt to befriend strangers or unwitting individuals. Many attempt to become social acquaintances with their professional contacts. In their effort to maintain the contacts and relationships they have developed, some individuals will overcompensate: calling their friend too many times, talking too long on the phone, demanding attention, and not being able to let up . . . .
>
> Friends can play a vital role in the adjustment to community living of adults who are retarded by providing the emotional support and guidance through the exigencies of daily life. Certain organizations have begun to address the need for friendship by initiating social opportunities . . . [There are] social club[s] for adults with retardation in which members plan their own parties and projects. Some programs offer supervised dating; others establish one-to-one relationships between volunteers and clients for the purpose of aiding adjustment. (Patton, Payne, & Beirne-Smith, 1990)

With the increase in mainstreaming, many hope the problems that numerous persons with mental retardation have in obtaining and holding friendships will decrease. In the future, it will be interesting to see to what degree professionals will organize social clubs exclusively for persons with mental retardation versus having them socialize with nondisabled persons.

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General Information About

DOWN SYNDROME

Definition

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

Incidence

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

Characteristics

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears;
- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a tendency to become obese as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

Educational and Employment Implications

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has proven successful. Improved public acceptance of persons with disabilities, along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group-shared and supervised apartments, and support services in the community have proven to be important resources for persons with disabilities.

Resources

Brill, M.T. (1993). *Keys to parenting a child with Down syndrome.* Hauppauge, NY: Barron's.

National Down Syndrome Congress. (1988). *Down syndrome* (revised pamphlet). (See address below.)

Pueschel, S.M. (Ed.). (1990). *A parent's guide to Down syndrome: Toward a brighter future.* Baltimore, MD: Paul H. Brookes. (Telephone: 1-800-638-3775.)

Stray-Gundersen, K. (1986). *Babies with Down syndrome: A new parent's guide.* Rockville, MD: Woodbine House. [Call Woodbine House at 1-800-843-7323 (outside DC area) or (301) 468-8800 (in DC area).]

National Down Syndrome Society. *This baby needs you even more.* (See address below.)

Organizations

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(404) 633-1555
(800) 232-6372 (Toll Free)

National Down Syndrome Society
666 Broadway
Suite 810
New York, NY 10012
(212) 460-9330
(1-800) 221-4602 (Toll Free)

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003; 1-800-433-5255

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For more information contact NICHCY.

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R. J. WAS MENTALLY RETARDED

BY MARY DEAN BARRINGER

As a 2nd grader, R. J. made numerous speech errors during oral reading and conversation. His teachers tried a variety of approaches to help him learn to read, but with little success. R. J. also needed step-by-step guidance to do simple seatwork. These problems, coupled with R. J.'s difficulties in auditory memory, prompted his 3rd-grade teacher, Chris Kramer, to suggest IQ testing. After some resistance, R. J.'s parents agreed to the testing, which confirmed that R. J. was educably mentally impaired.

OUR FIRST STEP WAS TO REASsure R. J.'s parents. My principal and I met with them and told them that the test results would guide us in making good, informed decisions about R. J.'s education. We assured them that we'd work with R. J. so he could go on to 4th grade with his friends. And they volunteered to be a tutor for R. J. and to help him with his homework each night.

Then, feeling that "less is more" was an appropriate guideline for a student like R. J., I concentrated on developing his basic math and language skills. Because language processing was difficult for R. J., I supplemented all oral directions with gestures or written cues. Not only did this benefit R. J., but my other students seemed to attend to directions more effectively as well. I'd also cue R. J.'s oral responses with open-ended sentences that helped him retrieve words, using sentence patterns such as "You saw the..." or "You liked the..." Visual reminders, such as an index card on his desk reminding him to put his name on each paper, helped him increase his independence as well as his ability to handle simple memory requirements.

Because R. J. was unsure of his own abilities, he tended to attach himself to one peer and imitate his work. But by eliciting R. J.'s own preferences, intentions, and interests, I helped him see himself as a valued class member with his own point of view. For example, I'd ask such questions as "R. J., do you have a favorite _____?" or "What do you think, R. J.?" I also assigned R. J. to a cooperative learning group that could work under my guidance to help him.

With the additional support of a speech therapist, who worked with him regularly on his language problems, and the tutoring provided by his parents, R. J. improved dramatically. By the end of the year, although not reading at grade level, he'd made enough progress to keep up with classmates and he was better able to do independent seatwork.

R. J.'s future success would depend on ongoing assessment and communication among the school's professionals and his parents. At the end of the year, with all the support techniques set up to continue, I confidently promoted him to 4th grade.

Resources

The Council for Exceptional Children, 1920 Association Dr., Reston, VA 22091, has information on educating children with exceptional needs.

Mary Dean Barringer, a former special education teacher, is currently the director of programs for the advancement of teaching for the National Board for Professional Teaching Standards.

VII. Learning Disabilities

- General Information about Learning Disabilities (NICHCY Fact Sheet)

- Misconceptions about Person with Learning Disabilities

- "I Couldn't Read Until I was 18"

NICHCY

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General Information About

LEARNING DISABILITIES

Definition

The regulations for Public Law (P.L.) 101-476, the Individuals with Disabilities Education Act (IDEA), formerly P.L. 94-142, the Education of the Handicapped Act (EHA), define a learning disability as a "disorder in one or more of the basic psychological processes involved in understanding or in using spoken or written language, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations."

The Federal definition further states that learning disabilities include "such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." According to the law, learning disabilities do not include learning problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural, or economic disadvantage. Definitions of learning disabilities also vary among states.

Having a single term to describe this category of children with disabilities reduces some of the confusion, but there are many conflicting theories about what causes learning disabilities and how many there are. The label "learning disabilities" is all-embracing; it describes a syndrome, not a specific child with specific problems. The definition assists in classifying children, not teaching them. Parents and teachers need to concentrate on the individual child. They need to observe both how and how well the child performs, to assess strengths and weaknesses, and develop ways to help each child learn. It is important to remember that there is a high degree of interrelationship and overlapping among the areas of learning. Therefore, children with learning disabilities may exhibit a combination of characteristics.

These problems may mildly, moderately, or severely impair the learning process.

Incidence

Many different estimates of the number of children with learning disabilities have appeared in the literature (ranging from 1% to 30% of the general population). In 1987, the Interagency Committee on Learning Disabilities concluded that 5% to 10% is a reasonable estimate of the percentage of persons affected by learning disabilities. The U.S. Department of Education (1993) reported that more than 4% of all school-aged children received special education services for learning disabilities and that in the 1991-92 school year over 2 million children with learning disabilities were served. Differences in estimates perhaps reflect variations in the definition.

Characteristics

Learning disabilities are characterized by a significant difference in the child's achievement in some areas, as compared to his or her overall intelligence.

Students who have learning disabilities may exhibit a wide range of traits, including problems with reading comprehension, spoken language, writing, or reasoning ability. Hyperactivity, inattention, and perceptual coordination problems may also be associated with learning disabilities. Other traits that may be present include a variety of symptoms, such as uneven and unpredictable test performance, perceptual impairments, motor disorders, and behaviors such as impulsiveness, low tolerance for fustruation, and problems in handling day-to-day social interactions and situations.

Learning disabilities may occur in the following academic areas:

1. Spoken language: Delays, disorders, or discrepancies in listening and speaking;
2. Written language: Difficulties with reading, writing, and spelling;
3. Arithmetic: Difficulty in performing arithmetic functions or in comprehending basic concepts;

4. Reasoning: Difficulty in organizing and integrating thoughts; and
5. Organization skills: Difficulty in organizing all facets of learning.

Educational Implications

Because learning disabilities are manifested in a variety of behavior patterns, the Individual Education Program (IEP) must be designed carefully. A team approach is important for educating the child with a learning disability, beginning with the assessment process and continuing through the development of the IEP. Close collaboration among special class teachers, parents, resource room teachers, regular class teachers, and others will facilitate the overall development of a child with learning disabilities.

Some teachers report that the following strategies have been effective with some students who have learning disabilities:

- Capitalize on the student's strengths;
- Provide high structure and clear expectations;
- Use short sentences and a simple vocabulary;
- Provide opportunities for success in a supportive atmosphere to help build self-esteem;
- Allow flexibility in classroom procedures (e.g., allowing the use of tape recorders for note-taking and test-taking when students have trouble with written language);
- Make use of self-correcting materials, which provide immediate feedback without embarrassment;
- Use computers for drill and practice and teaching word processing;
- Provide positive reinforcement of appropriate social skills at school and home; and
- Recognize that students with learning disabilities can greatly benefit from the gift of time to grow and mature.

Resources

Journal of Learning Disabilities. Available from Pro-Ed, 8700 Shoal Creek Blvd., Austin TX 78758. Telephone: (512) 451-3246.)

Silver, L. (1991). *The misunderstood child: A guide for parents of children with learning disabilities* (2nd ed.). New York, NY: McGraw Hill Book Co. (Available from McGraw Hill Retail, 13311 Monterey Lane, Blue Ridge Summit, PA 17294. Telephone: (717) 794-5461.)

Smith, S. (1981). *No easy answers.* New York, NY: Bantam Books. (Available from Bantam, 2451 South Wolf Rd., Des Plains, IL 60018. Telephone: 1-800-223-6834.)

Organizations

Council for Learning Disabilities (CLD)
P.O. Box 40303
Overland Park, KS 66204
(913) 492-8755

Division of Learning Disabilities
Council for Exceptional Children
1920 Association Dr.
Reston, VA 22091-1589
(703) 620-3660

Learning Disabilities Assn. of America (LDA)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515
(412) 341-8077

National Center for Learning Disabilities
99 Park Avenue
New York, NY 10016
(212) 687-7211

National Network of Learning Disabled Adults (NNLDA)
P.O. Box 32611
Phoenix, AZ 85064
(602) 941-5112

Orton Dyslexia Society
Chester Building, Suite 382
8600 LaSalle Road
Baltimore, MD 21286-2044
(410) 296-0232
(800) 222-3123 (Toll Free)

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MISCONCEPTIONS ABOUT PERSONS WITH LEARNING DISABILITIES

MYTH ≻ All students with learning disabilities are brain damaged.	**FACT** ≻ Although more students with learning disabilities show evidence of damage to the central nervous system (CNS) than their nondisabled peers, many of them do not. Many authorities now refer to students with learning disabilities as having CNS dysfunction, which suggests a malfunctioning of the brain rather than actual tissue damage.
MYTH ≻ IQ-achievement discrepancies are easily calculated.	**FACT** ≻ A complicated formula determines a discrepancy between a student's IQ and his or her achievement.
MYTH ≻ Standardized achievement tests are the most useful kind of assessment device for teachers of students with learning disabilities.	**FACT** ≻ Standardized achievement tests do not provide much information about why a student has achievement difficulties. Informal reading inventories and formative evaluation measures give teachers a better idea of the particular problems a student is experiencing.
MYTH ≻ We need not be concerned about the social-emotional well-being of students with learning disabilities because their problems are in academics.	**FACT** ≻ Many students with learning disabilities do also develop problems in the social-emotional area.
MYTH ≻ The most serious problem of children who are hyperactive is their excessive motor activity.	**FACT** ≻ Although children who are hyperactive do exhibit excessive motor activity, most authorities now believe that their most fundamental problems lie in the area of inattention.
MYTH ≻ Medication for children with attention-deficit disorder is over-prescribed and presents a danger for many children.	**FACT** ≻ Some children receive medication who do not need it, but there is little evidence that vast numbers are inappropriately medicated. Medication can be an important part of a total treatment package for persons with attention-deficit disorder.
MYTH ≻ Most children with learning disabilities outgrow their disabilities as adults.	**FACT** ≻ Learning disabilities tend to endure into adulthood. Even most of those who are successful must learn to cope with their problems and show extraordinary perseverance.

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Redbook Vol 167 (1) MAY, 1986

"I COULDN'T READ UNTIL I WAS 18"

Cher still can't spell or understand the words on a billboard. She has trouble dialing the phone and making change. At the age of 30 her problem was diagnosed as dyslexia. "Sometimes I feel so stupid. I don't know what I'd do if I had a regular job," she says. Here, for the first time, Cher talks about the disability that has caused her such pain.

BY LINDA KONNER

Cher, who has always exposed herself to merciless criticism for her hairdos, her clothes and her men, has recently opened herself up to further pain and humiliation by admitting publicly that she suffers from dyslexia. "I'm insecure about everything. It doesn't take much to shake my confidence to the bone," she says, and little wonder: The simplest tasks still baffle her. Her dyslexia made her school years a nightmare—she dropped out in 11th grade—and her acting career a struggle. Yet she has successfully managed to establish herself as an actress and is finally, at the age of 40, gaining the respect that has eluded her for so long.

Q. How did you feel when you first found out that you had dyslexia?

A. Suddenly things made a lot of sense. I never read in school. The first book I ever read was when I was 18 or 19 years old, and it was called *The Saracen Blade* by Frank Yerby. When I was in school, it was really difficult. Almost everything I learned, I had to learn by listening. I just couldn't keep up with everybody else. You can be really intelligent, but if you don't have a way of letting people know, you seem really stupid. My report cards always said that I was not living up to my potential. Teachers would see that I was a bright girl in class, and then I would hand in papers that you couldn't read. Also, I could never do the work quickly enough—most of the tests were timed.

Q. What were your grades like?

A. They were very sporadic. I got really bad grades—D's and F's and C's—in some classes, and A's and B's in other classes. My mother would get exasperated with me sometimes: She just could not understand why I could do so well in one class one semester and fail the next semester. And I never could understand it either. Some things were so difficult. But eventually I left school—in the second week of 11th grade. I just quit. I was sitting there one day and I just got up and said, "I'm not going back."

Q. It's understandable that you wouldn't like school if you were having such a hard time.

A. Well, I believe that, for the most part, school is a very boring place for very bright minds, you know? I think what school does half the time is cut out your creativity and just make you fit into society. I don't think school is the place to really learn very much. It's evident if you see what's happening in the country—you know, there are so many people who can't pass a civil service exam, or can't read. In Los Angeles, instead of using the word *Walk* [on street signs], they show a person walking, because some people can't read a sign.

Q. When was your dyslexia condition first diagnosed?

A. When I was 30.

Q. You found out about it when you took Chastity to be tested?

A. Yes. She's very intelligent, but she just did so badly in school, and she was having such a hard time. Then I sent her to a special school, which was really a drag, because a lot of the kids in the school had emotional problems and she doesn't. But she just felt that she was stupid because her oral scores were so much higher than her written scores.

Q. What did you do next?

A. One of the doctors who had tested her recommended that I take her to a dyslexia center in Santa Monica. When I went in there, I said to the lady, "I know Chastity is really smart—she's just like me." The woman said, "What do you mean?" and we started talking about it, and that's when we found out we both had it.

Q. Now that Chastity understands the problem, she must feel better.

A. Yes, she feels a lot better. She's now go-

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ing to the High School of Performing Arts and she's doing great, but she has to work really hard at it. She has to study longer than most kids with her amount of intelligence. That's the problem, you know.

Q. As for your dyslexia, how does it affect you now on a day-to-day basis?
A. There are still things that I do that make me feel really stupid. Like, the other day I couldn't figure out how much money to give the cab driver. In my mind what I did made sense, but he was just furious that I didn't give him a decent tip. Dialing long distance is difficult. If I really concentrate on it, I can do it. But if there's a number—for example, 472, I'll see 427. And the more numbers there are, the harder it is for me to retain them in sequence. And I see billboards that don't exist. Like, I'll see four words on a billboard, and I'll just put them together in my own way. It'll make sense to me, but it won't have anything to do with what the billboard actually says.

Q. Once you were diagnosed, did doctors do anything to help you?
A. No, but I've pretty much got my own way of handling it. Like the reading—I read very slowly. Now, if I read a script once, I know it, I almost never have to look back at it. I guess your brain compensates. If I had a regular job—one that uses skills that most people have to use, like eye-word, eye-number skills—I don't know what I'd do. But for what I do, the way I read is only an inconvenience.

Q. What about reading from cue cards while you're performing?
A. I don't do that.

Q. How did you handle that when you were doing your TV shows?
A. Sonny read the cards and I studied the script.

Q. Did you ever find yourself in an embarrassing situation involving your dyslexia?
A. (laughs) Yes. I once went on an audition for a movie. I was supposed to meet the director and talk to him about a part, and he was going to see if I was right for it. Because he thought I was perfect, he wanted me to read. And I said, "I don't do this well." But he gave me the script. Then Jack Nicholson [the star of the movie] walks in. We were sitting there, and I started to read, and I am trying to explain to them that I don't do this well at all. But they didn't want to know about it. So we start to read, and when I was done, the director said, "It's a good thing I saw you in *Silkwood* yesterday, because that is definitely the worst cold reading I have ever heard." And I said, "Well, you know, I told you that's not what I do well."

(continued on page 174)

Cher, who turns 40 this month, suffers from dyslexia, as does her teenage daughter, Chastity.

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"I COULDN'T READ UNTIL I WAS 18"

continued from page 125

Q. Did you explain why?
A. Not really, because it was a tense moment. It was terrible. I didn't get the part!

Q. How do you feel about doing cold readings for directors now?
A. I wouldn't do them now. I would never cold read for anybody. Look, in *Mask* I tested, and I k.... what I was doing. It's like, I saw a show once where they were looking for tap dancers. There was this little boy from Spain, and he needed a job, and he was a flamenco dancer. He tried to tap dance, but he couldn't do it. But then, when he did what he *could* do, he did it better than all the people that were trying out for the tap dancing job. So it just wouldn't make sense for me to try to cold read if what they wanted to do was see what I did well.

Q. Now that there's no pressure on you to read, do you ever read for pleasure? Or is it still a struggle?
A. I read for pleasure constantly. I'm reading four books right now. I'm reading *The Mammoth Hunters;* I read the first two [Jean Auel books]. I'm reading *The Vampire Lestat.* I'm reading *Goddess* and *Drama of the Gifted Child,* a psychology book my boyfriend Josh [Donen] gave me.

Q. How do you feel now that the public knows about your dyslexia?
A. I could care less.

Q. What about your feelings about your image in general?
A. The way I dress and the way I look are my sense of expression and creativity; I don't feel like stifling that for anybody. I mean, I was going to get a Mohawk haircut one time, and Chastity threw herself against the door. She said, "You know, *you* should be doing this to *me.* I should be the one that wants a Mohawk, and you should be saying no." It's like, if Chas wants to dye her hair green and purple, it shouldn't make any difference; it's an expression of who she is. It's like that for me too. So I have a major reputation. It's amazing what a hairdo can give you! People think I'm really crazy because of the way I look. I think that's . . . crazy.

Q. How do you think your image affects your children?
A. I think they're much cooler than most people. I think they're both very proud of me. They think I'm outrageous, and they laugh at the way I am sometimes; they get a kick out of me.

Q. Perhaps they can understand the way you dress because you're their mother and they love you. But what about the comments they may hear about you from their friends, or from strangers?
A. Chas goes to a school where the students are actors and actresses, and they're all pretty much into the work I do. Chas is really well-liked in school for herself, but I also remember that when *Mask* came out, her friends said, "Oh, Chas, I loved your mom in the movie." You know, lots of her friends have Mohawks. Kids are not as judgmental as adults. So most of Chas' friends think I'm really cool because I'm an adult, but I don't exactly look like an adult . . . whatever that's supposed to mean.

As for Elijah . . . One day he came home and he was really upset. He said, "So-and-so's grandmother said you're a whore." And I said, "Well, that's interesting. What did she base that on?" And he said, "I don't know, but I'm not going to talk to him anymore." We talked about it for a long time; I could tell he was pretty upset. But later, he came to the conclusion that he lives with me and he knows what kind of person I am. He realized that this woman was having a rough time in her life, and that it didn't have much to do with him or me.

Q. Does Chastity generally accept you better than Elijah does?
A. Yes. I think boys are just so much more vulnerable than girls. Chastity's always had the most amazing inner strength. She's never really liked [other] kids that much; she's always been around adults and had an adult kind of philosophy about things. The only thing I can ever remember her being really upset about lately was when she got into the High School of Performing Arts. Right afterward the school got all this video equipment, and some kids started a rumor that Chastity got in because I bought all the equipment. She was really angry about that. But I don't think the way I've led my life has interfered with her that much. It might have when we were back in California, when I was leaving her father. I know that was a real difficult time for her.

Q. How did you explain your breakup with Sonny to Chastity?
A. Well, until recently—maybe a couple of years ago—I never said very much to her about Sonny. I try to be really positive, because she felt bad that he hadn't done as well [as I had] after the breakup. One day she was giving me some flak because I didn't invite her father to something—and I said, "You know, I've never said anything bad about your father and I've never gone into any of the reasons. But you're old enough for me to tell you that it's impossible for me to be friends with your father, because I just don't like him."

Q. How old was she when you said that?
A. About 15½.

Q. How did she take it?
A. She wasn't crazy about it at all.

Q. It must be hard for a child to hear that her parents don't like each other.
A. Oh, I'm sure of it. But, the truth is, you can only be hurt in your life by someone so much, and then you have to protect yourself or it doesn't make any sense. For me to be around Sonny is like walking into a fire.

Q. How would you describe the relationship you had with Sonny?
A. It was like I was a black person working on a plantation for a benevolent boss. Without your freedom, it doesn't make any difference who your master is. For a long time, I acted toward him in a way that was very different from the way I felt. And I'm sorry I feel this way—I would prefer to be absolutely friendly and enjoy being around him. It would make my life a lot easier. But I don't think I ever knew Sonny at all. First of all, what can you know at 16? Not very much. But also, he didn't want to share himself. He thought that if I knew about him, I would have some kind of power that he just wasn't ready to give up. That's something we all do, but [to be doing that for] 11 years is a long time. I mean, if you can't trust someone . . . He was 28 when I met him, and he'd been trying for 10 years to be a singer. Then, all of a sudden, in a matter of a year, we became famous. He said that he knew from the time he saw me that it was going to happen. But he was always afraid that if I knew I was talented or pretty or any of the other things he thought I was, that I would leave him. I've been working on a song for a new album; it's really autobiographical. I've got one verse in there about Sonny he's not going to like at all. It goes:

He stole life and heart and beauty,
Said he did it for my good,
Said he always knew I'd leave him,
So he crushed me while he could.
There's no answers, there's no justice,
There's just eyes too blind to cry.
It's no wonder I'm the phoenix,
My salvation that I've died.

Q. You feel then that he withheld from you the encouragement you really needed?
A. You know, it was strange—he gave it on certain levels, like on a work level. He was always saying, "You can do it" [about my work]. That's why we made better [business] partners than husband and wife. If we had only stuck to working together, it would have been great.

Q. What do you think about the whole idea of marriage now?
A. Marriage doesn't interest me. It would if it was important to someone that I cared about. As something that *I'm* seeking? I don't know if it works for me. I don't know if I'm ready to be married.

(continued on page 177)

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"I COULDN'T READ UNTIL I WAS 18"

continued from page 174

Q. Even as you turn 40, even after two marriages?
A. As I was turning 30 I was a lot more ready to be married; I *was* married [to rock singer Gregg Allman]. Marriage sounds fabulous in theory. But the kind of work I'm in is not exactly noted for long-lasting relationships of any kind.

Q. Would you say your work makes you self-centered?
A. I'm certainly self-centered, but I'm really giving in a relationship; while I'm in it, it's very important. I mean, I'm not perfect, but as a partner I think I'm really loving and giving. It's just that it only lasts so long.

Q. Does that mean you don't think anybody can sustain a good relationship over a long period of time?
A. Look, I sustained a *bad* relationship over a long period of time. The older I get, the less patience I've got for sustaining anything that doesn't work over a long period of time. If it worked—and I'm willing to work on things—I would be in it for a long time. But I also want to be creative, and I don't know that creativity necessarily has too much to do with marriage. I also like to spend a lot of time alone.

Q. How do you spend your time alone?
A. I like to read. I like to exercise. I like to write. I like the freedom of not having to answer to anybody. You know, I think that being with Sonny did a lot of things that were not so healthy for me—I mean, I had to have a reasonable place to go to before I could [get permission from Sonny to] go out of the house. And because of that, I've had a big backlash. I don't want anybody to ask me where I'm going—if I want to go someplace, I really want to do it. Thank God, I have my kids; kids are usually so much more understanding than husbands. For example, when I was doing *Mask*, I would get up at 5:30 in the morning, and I would work out for an hour until I was picked up to go to the studio. I would come home at 7:30 at night, and I would fall into bed. I couldn't give anything to anyone. The kids would come and sit on the bed, and we'd talk—sometimes I'd fall asleep talking. I didn't even have that much energy to give them on weekends. It's hard to explain that to a man, because he'd take it personally.

Q. Does your wanting to stay single have anything to do with sex—a desire to avoid sexual fidelity?
A. No. I'm so monogamous it's disgusting. I'm not very liberated or New Age; if I find somebody that I really like, I just don't want to be with anybody else. I'm not a dater at all. I have such a reputation; it's just that my relationships are publicized.

Q. What's your ideal man like?
A. I've just been with the ideal man. His name is Josh Donen, and he's the most fabulous man I've ever known. He's bright, we're in the same business [he's a movie producer], we've got everything to talk about, he's handsome, he cracks me up constantly, he's a fabulous father to my kids. There's nothing wrong with him. Even my mother is crazy about him. She says, "Cher, come home to California. Don't stay in New York; are you crazy? What's the matter with you?" I've never met anybody like him. He's like a dream man. He's a prince.

Q. So what's the problem?
A. His work keeps him stuck in L.A.; he has an extremely demanding job. And whenever I come to New York, I really want to be here. It's so hard for me to live in Los Angeles; I really don't like it there. Also he wants to get married—and that just really scares me to death.

Q. If there were one thing about yourself that you could change, what would it be?
A. I would not want to be so insecure. That insecurity stifles everything. As I go on in life, I become more secure in some areas and less secure in others that I used to be more secure in. I guess it's a trade-off.

Q. What are you most insecure about?
A. Everything from my ability as an actress to my ability as a mother to how I look. It doesn't take much to shake my confidence to the bone. But then I keep coming back. So, if I'm going to keep coming back, I would just like to tell myself once and for all that I'll be okay, so I don't have to keep going through the drama.

Q. Do you think your ability to bounce back makes people like you?
A. Yes. I'm a survivor, and people respect that. You know, I was about as down and out as anyone can be in my profession [after the TV shows went off the air], and all of a sudden, I just came back to life. I've done that a whole bunch of times. Also, people kind of like me in spite of myself.

Q. What do you mean?
A. I'm one of those people that's kind of likable; you just kind of like them. For instance, when I go on the *Donahue* show, I always think, "Oh, these women are going to kill me." And yet, they don't. Part of it is because I'm not totally full of sh.... I don't really hide my mistakes—I mean, it would be impossible to try to hide them. But I feel like I have some kind of special dispensation. People like me in spite of the fact that if they saw me walking down the street and I wasn't Cher, they wouldn't like me at all. ●

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½ tsp. Dijon mustard
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Chopped pimiento
In 1½ qt. saucepan over medium heat, stir soup. Stir in broccoli, sour cream and mustard. Heat thoroughly; stir occasionally. Split potatoes; fluff with fork. Serve sauce over potatoes. Garnish with chopped pimiento. 4 servings.
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VIII. Visual Impairments

- General Information about Visual Impairments (NICHCY Fact Sheet)
- Misconceptions about Persons with Visual Impairments
- How Not to Help A Person Who is Blind and Lost
- Mainstreaming Case History: Troy was Blind
- America's Boswell Drives Into the Dark

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free) (202) 416-0300 (Local, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

General Information About

VISUAL IMPAIRMENTS

Definition

The terms partially sighted, low vision, legally blind, and totally blind are used in the educational context to describe students with visual impairments. These terms are defined as follows:

- "Partially sighted" indicates some type of visual problem has resulted in a need for special education;
- "Low vision" generally refers to a severe visual impairment, not necessarily limited to distance vision. Low vision applies to all individuals with sight who are unable to read the newspaper at a normal viewing distance, even with the aid of eyeglasses or contact lenses. They use a combination of vision and other senses to learn, although they may require adaptations in lighting, the size of print, and, sometimes, braille;
- "Legally blind" indicates that a person has less than 20/200 vision in the better eye or a very limited field of vision (20 degrees at its widest point); and
- Totally blind students, who learn via braille or other non-visual media.

Visual impairment is the consequence of a functional loss of vision, rather than the eye disorder itself. Eye disorders which can lead to visual impairments can include retinal degeneration, albinism, cataracts, glaucoma, muscular problems that result in visual disturbances, corneal disorders, diabetic retinopathy, congenital disorders, and infection.

Incidence

The rate at which visual impairments occur in individuals under the age of 18 is 12.2 per 1,000. Severe visual impairments (legally or totally blind) occur at a rate of .06 per 1,000.

Characteristics

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appears, and overall functioning level of the child. Many children who have multiple disabilities may also have visual impairments resulting in motor, cognitive, and/or social developmental delays.

A young child with visual impairments has little reason to explore interesting objects in the environment and, thus, may miss opportunities to have experiences and to learn. This lack of exploration may continue until learning becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or understand nonverbal cues. Visual disabilities can create obstacles to a growing child's independence.

Educational Implications

Children with visual impairments should be assessed early to benefit from early intervention programs, when applicable. Technology in the form of computers and low-vision optical and video aids enable many partially sighted, low vision, and blind children to participate in regular class activities. Large print materials, books on tape, and braille books are available.

Students with visual impairments may need additional help with special equipment and modifications in the regular curriculum to emphasize listening skills, communication, orientation and mobility, vocation/career options, and daily living skills. Students with low vision or those who are legally blind may need help in using their residual vision more efficiently and in working with special aids and materials. Students who have visual impairments combined with other types of disabilities have a greater need for an interdisciplinary approach and may require greater emphasis on self care and daily living skills.

Resources

American Foundation for the Blind. (1993). *AFB directory of services for blind and visually impaired persons in the United States and Canada* (24th ed.). New York, NY: Author.

Curran, E.P. (1988). *Just enough to know better (A braille primer).* Boston, MA: National Braille Press.

Dodson-Burk, B., & Hill, E.W. (1989). *An orientation and mobility primer for families and young children* (Item 1576). New York, NY: American Foundation for the Blind.

Ferrell, K.A. (1985). *Reach out and teach: Materials for parents of visually handicapped and multi-handicapped young children* (Item 2084). New York: American Foundation for the Blind.

Hazekamp, J., & Huebner, K.M. (1989). *Program planning and evaluation for blind and visually impaired students: National guidelines for educational excellence* (Item 155x). New York, NY: American Foundation for the Blind.

Holbrook, M.C. (Ed.). (in press). *Children with visual impairments: A parents' guide*. Rockville, MD: Woodbine. [Telephone: 1-800-843-7323 (outside DC area); (301) 468-8800 (in DC area).]

Huebner, K.M.,& Swallow, R.M. (1987). *How to thrive, not just survive: A guide to developing independent life skills for blind and visually impaired children and youth* (Item 1487). New York, NY: American Foundation for the Blind.

Scott, E., Jan, J., & Freeman, R. (1985). *Can't your child see?* (2nd ed.). Austin, TX: Pro-Ed. [Available from Pro-Ed, at (512) 451-3246.]

Organizations

American Council of the Blind Parents
c/o American Council of the Blind
1515 15th St. N.W., Suite 720
Washington, D.C. 20005
(202) 467-5081; (1-800) 424-8666

American Foundation for the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000; (1-800) AFBLIND (Toll Free Hotline)
For publications, call: (718) 852-9873

Blind Children's Center
4120 Marathon Street
Los Angeles, CA 90029-0159
(213) 664-2153; (1-800) 222-3566

Division for the Visually Handicapped
c/o Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660

National Association for Parents of the Visually Impaired, Inc.
P.O. Box 317
Watertown, MA 02272
(817) 972-7441

National Association for Visually Handicapped
22 West 21st Street, 6th Floor
New York, NY 10010
(212) 889-3141

National Braille Association, Inc. (NBA)
1290 University Avenue
Rochester, NY 14607
(716) 473-0900

National Braille Press
88 St. Stephen Street
Boston, MA 02115
(617) 266-6160; (1-800) 548-7323

National Eye Institute
National Institutes of Health
U.S. Department of Health & Human Services
Building 31, Room 6A32
Bethesda, MD 20892
(301) 496-5248

National Federation of the Blind, Parents Division
c/o National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314

National Library Services for the Blind and Physically Handicapped
Library of Congress
1291 Taylor Street, N.W.
Washington, D.C. 20542
(202) 707-5100; (1-800) 424-8567

National Retinitis Pigmentosa Foundation
1401 Mt. Royal Avenue, Fourth Floor
Baltimore, MD 21217
(410) 225-9400; (410) 225-9409 (TT)
(1-800) 683-5555 (Toll Free)

National Society to Prevent Blindness
500 E. Remington Road
Schaumburg, IL 60173
(708) 843-2020; (1-800) 221-3004 (Toll Free)

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MISCONCEPTIONS ABOUT PERSONS WITH VISUAL IMPAIRMENTS

MYTH ➢ People who are legally blind have no sight at all.

FACT ➢ Only a small percentage of those who are legally blind have absolutely no vision. Many have a useful amount of functional vision.

MYTH ➢ People who are blind have an extra sense that enables them to detect obstacles.

FACT ➢ People who are blind do not have an extra sense. Some can develop an "obstacle sense" by noting the change in pitch of echoes as they move toward objects.

MYTH ➢ People who are blind automatically develop better acuity in their other senses.

FACT ➢ Through concentration and attention, individuals who are blind can learn to make very fine discriminations in the sensations they obtain. This is not automatic but rather represents a better use of received sensations.

MYTH ➢ People who are blind have superior musical ability.

FACT ➢ The musical ability of people who are blind is not necessarily better than that of sighted people but many people who are blind pursue musical careers as one way in which they can achieve success.

MYTH ➢ Braille is not very useful for the vast majority of people who are blind; it should only be tried as a last resort.

FACT ➢ Very few people who are blind have learned Braille, primarily due to fear that using Braille is a sign of failure and to an historical professional bias against Braille. Authorities acknowledge the utility of Braille for people who are blind.

MYTH ➢ Braille is of no value for those who have low vision.

FACT ➢ Some individuals with low vision have conditions that will eventually result in blindness. More and more, authorities think that these individuals should learn Braille to be prepared for when they cannot read print effectively.

MYTH ➢ If people with low vision use their eyes too much, their sight will deteriorate.

FACT ➢ Only rarely is this true. Visual efficiency can actually be improved through training and use. Wearing strong lenses, holding books close to the eyes, and using the eyes often cannot harm vision.

MYTH ➢ Mobility instruction should be delayed until elementary or secondary school.

FACT ➢ Many authorities now recognize that even preschoolers can take advantage of mobility instruction, including the use of a cane.

MYTH ➢ The long cane is a simply constructed, easy to use device.

FACT ➢ The National Academy of Sciences has drawn up specifications for the manufacture of the long cane and using it properly.

MYTH ➢ Guide dogs take people where they want to go.

FACT ➢ The guide dog does not "take" the person anywhere; the person must first know where he or she is going. The dog is primarily a protection against unsafe areas or obstacles.

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HOW NOT TO HELP A PERSON WHO IS BLIND AND LOST

When the sighted encounter someone who is lost, their natural inclination is to ask the person where he or she is headed. As the following entry in the diary of John M. Hull (1990) indicates, this question can lead to confusion when the person lost happens to be blind.

GETTING LOST — 8 November

I think it is David Scott Blackhall, in his autobiography *The Way I See Things* (London, Baker, 1971), who remarks how annoying he found it when people refused to answer his question about where he was and insisted on asking him where he was trying to get to. I share this experience.

Going home the other night I was turned out of my way by some construction work on one of the footpaths. By mistake I turned along a side street, and after a block or so, when I realized I had made a mistake somewhere, I was not sure exactly where I was. There were some chaps working on a car parked on the roadside. 'Excuse me', I said. 'Could you tell me please where I am? What is the name of this street?'

The chap replied, 'Where are you trying to get to?'

With what I hoped was a good-humored laugh, I said, 'Never mind about that, just tell me, please, what street this is?'

'This is Alton Road, You usually go up Bournbrook Road, don't you? It's just a block further along.'

I thanked him, and explained that I needed now to know exactly whereabouts on Alton Road I was so that I could get to Bournbrook Road. 'Which side of Alton Road am I on? If I face that way, am I looking towards Bristol Road or is it the other way?'

'You live high up Bournbrook Road, don't you? Well, if you take the next road to the left you'll be OK.'

But which way is 'left'? Does he mean me to cross the road or to stay on this side? At this point, the blind and sighted enter into mutual bafflement.

When a sighted person is lost, what matters to him or her is not where he is, but where he is going. When he is told that the building he is looking for lies in a certain direction, he is no longer lost. A sighted person is lost in the sense that he does not know where the building he is looking for is. He is never lost with respect to what street he is actually on; he just looks at the street sign on the corner of the block. It is his direction he has lost, rather than his position. The blind person lost has neither direction nor position. He needs position in order to discover direction. This is such a profound lostness that most sighted people find it difficult to imagine.

SOURCE: From *Touching the rock* by John M. Hull. Copyright © 1990 by John M. Hull. Reprinted by permission of Pantheon Books, a division of Random House, Inc., pp. 144–145.

MAINSTREAMING

CASE HISTORY

TROY

Troy may have been born blind, but when he entered Eileen Walcik's 7th-grade reading class at Smith Middle School, he could see his goal clearly—to be the same as the other students. All his life, Troy had worked extra hard to keep up with kids his age. He'd taught himself to skateboard, mastered the drums, and learned music by ear. Now, at the age of 13, fitting in had become even more important. Walcik quickly found that the challenge of helping Troy required *her* to see new ways of doing things.

ALTHOUGH I'D BEEN TEACHING for more than 10 years, I was apprehensive about having a blind student in my class. How would I adapt my lessons to meet Troy's needs *and* my other students' needs? How could Troy participate in all our activities?

My state's school for the blind would provide braille textbooks for Troy. But the school didn't provide braille work sheets or supplementary materials, so I had to either send these to the school to be converted to braille or figure out a way to adapt them. And I always needed a backup plan in case the materials didn't arrive in time.

When I met Troy, I found him to be friendly, outgoing, and eager to learn. He quickly found his way around, and I could tell by his facial expressions that he was excited to be in school.

I soon realized that Troy was an extremely skillful listener. I planned more oral lessons and tests so Troy could work with the rest of the class. His listening skills saved the day once when we completed our assignments early and the other students asked to read a play. We didn't have a braille copy, but I asked another student to prompt him, and Troy was able to play a part. His face glowed.

Our unit on graphs and diagrams brought new challenges. But I was able to make this unit tactile so Troy could read the information. I made circle graphs using heavy-duty aluminum foil and a dressmaker's wheel and bar graphs using tiny pinpricks on heavy braille paper. The school for the blind added the statistics in braille.

I used textured materials to make diagrams for Troy. For one unit, I made a diagram of rock layers using a smooth section, one with dots of glue, and one with tiny pinpricks.

Because Troy couldn't see the pictures in our books, I had his classmates describe them to him in detail. Not only did Troy understand the information better, but so did the rest of the class.

Art is an area that's traditionally closed to blind students. My students loved illustrating stories we read, and I could see that Troy wanted to try drawing too. When we read *The Lion, the Witch, and the Wardrobe,* I found I had a tape of songs to go with the book. I gave my students paper and asked them to close their eyes, listen, and draw to the flow of the music—all without peeking. Troy was excited when the other students found pictures in his drawing.

Throughout that school year, my class and I learned to look at our world in a new way. Troy taught us that, with some extra effort, a positive attitude, and a little help from friends, a blind student could do anything we could do—and more. ❍

TROY WAS BLIND

Eileen Walcik teaches 6th- and 7th-grade English and reading (talented and gifted) at Smith Middle School in Fort Hood, Tex.

AMERICA'S BOSWELL DRIVES INTO THE DARK

DUDLEY DOUST ON A REMARKABLE PLAYER

After he had stooped to feel the texture of the grass, and finger the edge of the cup, Charley Boswell paced with his caddie across the green to his ball. He counted as he went . . . 48, 49, 50 feet. "It's mostly downhill," said his caddie, crouching to line up the face of Boswell's putter. "Take off about 10 feet, and putt it like a 40-footer."

Boswell stroked the ball. It sped across the green, climbed and fell, curved, slowed down and dropped with a rattle into the hole. Boswell grinned: "Did you see that one?" Yes, I had seen it. But he hadn't. Charley Boswell is blind. In fact, he is one of the most remarkable blind sportsmen in the world and playing off a handicap as low as 12, he has won the United States Blind Golfers' Association Championship 17 times.

Putting, oddly enough, is one of Boswell's strong departments. Given, of course, the fact that his caddie reads the putt, his execution is immaculate. "A tip that we blind golfers can pass on to the sighted player," he said, "I don't worry about the breaks on a green. Don't try to curb your putt because, as Bobby Jones always said, every putt is a straight putt and let the slopes do the work."

A few weeks ago I met Boswell in California, where he was playing a benefit match for the Braille Institute of America. He had come up from Alabama, where he is the State Commissioner in the Department of Revenue, a remarkable enough job, and now he was walking to the second tee on a course in the lush Coachelle Valley. A wind blew down from the mountains. "Funny thing," he said, "wind is really the only thing that bothers me. It affects my hearing, and that ruins my sense of direction."

On the second tee his caddie, who is his home professional back in Alabama, lined up the face of Boswell's driver and stepped away. Boswell, careful not to lose this alignment, did not waggle his clubhead. He paused, setting up some inner rhythm, and swung with the certainty of a sighted player. He groaned as the ball tailed off into a slice.

"There are two ways I can tell if I hit a good shot," he said, frowning. "I can feel it through the clubhead and, more important, I finish up high on my follow-through. Come on, let's walk. I can't stand golf carts—they bother my judgment of distance."

Boswell has been walking down darkened fairways since shortly after the Second World War. Blinded when a German antitank gun scored a direct hit on his vehicle in the Ruhr, he was sent back to an American hospital for rehabilitation. A former gridiron footballer and baseball player, Boswell did not take easily to pampered, supervised sport.

"I tried swimming, and it bored me. I tried horseback riding until I rode under a tree and got knocked off. I tried ten-pin bowling, and that wasn't any good either—I fell over the ball-track." He laughed, idly swinging his club as he walked. "Then one day this corporal came in and suggested we play golf. I told him to get the hell out of my room."

Boswell had never swung a golf club in his life but, a few days later, aged 28, he gave it a try: "He handed me a brassie. I took six practice swings, and then he teed one up and I hit it dead centre, right out of the sweet spot. I tell you, I was lucky. If I'd missed the ball that first time I would have quit golf." There are no false heroics about Boswell.

Some holes later he, or rather we, found his ball in a bunker. The bunker shot was clearly the most difficult shot in Boswell's bag. Playing it required him to break two Rules of Golf: he not only needed his usual help from someone to line up his club but, to avoid topping the ball, or missing it altogether, he had to ground his club in the sand. "Also, I can't get fancy and cut across the ball," he said. "I have to swing square to the line of flight. I have to play it like an ordinary pitch."

These handicaps, he later pointed out, were in part counterbalanced by the actual advantages of being blind on a golf course. Boswell, for instance, is never tempted to play a nine-iron when a seven-iron will do the job. "In a match blind players play the course, not their opponents, because we can't see what they're doing anyway," he said, on the way to a score of 91 which, for him, was neat but not gaudy. "You know, I was once playing with Bob Hope, and he said: 'Charley, if you could see all the trouble on this golf course, you wouldn't be playing it.' And I suppose he was right."

SOURCE: Dudley Doust, *Sunday Times*, London, February 6, 1977. Reprinted by permission.

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IX. Hearing Impairments

- Deafness: A Fact Sheet (NICD Sheet)

- Misconception about Persons with Hearing Impairments

- Up To The Challenge

National Information Center on Deafness

NEW PHONE NUMBER
(202) 416-0300 (VOICE/TT)

DEAFNESS: A FACT SHEET

This fact sheet was written cooperatively by the National Information Center on Deafness and the National Association of the Deaf.

Introduction

An estimated 21 million Americans have some degree of hearing impairment. Hearing impairments affect individuals of all ages, and may occur at any time from infancy through old age. The degree of loss may range from mild to severe. This variability in age at onset and degree of loss plus the fact that each individual adjusts differently to a loss of hearing makes it impossible to define uniformly the consequences of a loss.

Although the National Center for Health Statistics through its Health Interview Survey has been able to estimate the number of people with hearing impairments, there have been no recent national surveys which can be used to estimate the number of people who are deaf. As a result, estimates for the number of deaf people range anywhere from 350,000 to two million.

Audiological/Medical Information

There are four types of hearing loss, each of which can result in different problems and different possibilities for medical and nonmedical remediation.

Conductive hearing losses are caused by diseases or obstructions in the outer or middle ear (the conduction pathways for sound to reach the inner ear). Conductive hearing losses usually affect evenly all frequencies of hearing and do not result in severe losses. A person with a conductive hearing loss usually is able to use a hearing aid well, or can be helped medically or surgically.

Sensorineural hearing losses result from damage to the delicate sensory hair cells of the inner ear or the nerves which supply it. These hearing losses can range from mild to profound. They often affect certain frequencies more than others. Thus, even with amplification to increase the sound level, the hearing impaired person perceives distorted sounds. This distortion accompanying some forms of sensorineural hearing loss is so severe that successful use of a hearing aid is impossible.

Mixed hearing losses are those in which the problem occurs both in the outer or middle and the inner ear.

A **central** hearing loss results from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself.

Among the causes of deafness are heredity, accident, and illness. An unborn child can inherit hearing loss from its parents. In about 50 percent of all cases of deafness, genetic factors are a probable cause of deafness. Environmental factors (accident, illness, ototoxic drugs, etc.) are responsible for deafness in the remaining cases. Rubella or other viral infections contracted by the pregnant mother may deafen an unborn child. Hazards associated with the birth process (for example, a cut-off in the oxygen supply), may affect hearing. Illness or infection may cause deafness in young children. Constant high noise levels can cause progressive and eventually severe sensorineural hearing loss, as can tumors, exposure to explosive sounds, heavy medication, injury to the skull or ear, or a combination of these factors.

Central hearing loss may result from congenital brain abnormalities, tumors or lesions of the central nervous system, strokes, or some medications that specifically harm the ear.

The detection and diagnosis of hearing impairment have come a long way in the last few years. It is now possible to detect the presence of hearing loss and evaluate its severity in a newborn child. While medical and surgical techniques of correcting conductive hearing losses have also improved, medical correction for sensorineural hearing loss has been more elusive. Current research on a cochlear implant which provides electrical stimulation to the inner ear may lead to important improvements in the ability to medically correct profound sensorineural hearing loss.

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Educational Implications

Deafness itself does not affect a person's intellectual capacity or ability to learn. Yet, deaf children generally require some form of special schooling in order to gain an adequate education.

Deaf children have unique communication needs. Unable to hear the continuous, repeated flow of language interchange around them, deaf children are not automatically exposed to the enormous amounts of language stimulation experienced by hearing children during their early years. For deaf children, early, consistent, and conscious use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay. Without such assistance from infancy, problems in the use of English typically persist throughout the deaf child's school years. With such assistance, the language learning task is easier but by no means easy.

This problem of English language acquisition affects content areas as well. While the academic lag may be small during the primary grades, it tends to be cumulative. A deaf adolescent may be a number of grade levels behind hearing peers. However, the extent to which hearing impairment affects school achievement depends on many factors—the degree and type of hearing loss, the age at which it occurred, the presence of additional handicaps, the quality of the child's schooling, and the support available both at home and at school.

Many deaf children now begin their education between ages one to three years in a clinical program with heavy parental involvement. Since the great majority of deaf children—over 90 percent—are born to hearing parents, these programs provide instruction for parents on implications of deafness within the family. By age four or five, most deaf children are enrolled in school on a full-day basis. Approximately one-third of school-age deaf children attend private or public residential schools. Some attend as day students and the rest usually travel home on weekends. Two-thirds attend day programs in schools for the deaf or special day classes located in regular schools, or are mainstreamed into regular school programs. Some mainstreamed deaf children do most or all of their schoolwork in regular classes, occasionally with the help of an interpreter, while others are mainstreamed only for special activities or for one or two classes.

In addition to regular school subjects, most programs do special work on communication and language development. Class size is often limited to approximately eight children to give more attention to the children's language and communication needs.

At the secondary school level, students may work toward a vocational objective or follow a more academic course of study aimed at postsecondary education at a regular college, a special college program for deaf students (such as Gallaudet University or the National Technical Institute for the Deaf) or one of the 100 or more community colleges and technical schools that have special provisions for deaf students.

Communication: Some Choices

Communication is an important component of everyone's life. The possible choices for communication involve a variety of symbol systems. For example, you may communicate in English through speaking and writing. Despite your skills, you probably cannot communicate with someone whose only language is Chinese, even though that person also speaks, reads, and writes quite fluently.

In the United States, deaf people also use a variety of communication systems. They may choose among speaking, speechreading, writing, and manual communication. Manual communication is a generic term referring to the use of manual signs and fingerspelling.

American Sign Language

American Sign Language (ASL) is a language whose medium is visible rather than aural. Like any other language, ASL has its own vocabulary, idioms, grammar, and syntax—*different from English*. The elements of this language (the individual signs) consist of the handshape, position, movement, and orientation of the hands to the body and each other. ASL also uses space, direction and speed of movements, and facial expression to help convey meaning.

Fingerspelling

When you spell with your fingers, you are in effect "writing in the air." Instead of using an alphabet written on paper, you are using a manual alphabet, that is, one with handshapes and positions corresponding to each of the letters of the written alphabet.

Conversations can be entirely fingerspelled. Among deaf people, however, fingerspelling is more typically used to augment American Sign Language. Proper names and terms for which there are no signs are usually fingerspelled. In the educational setting, the use of fingerspelling as the primary mode of communication in combination with spoken English is known as the Rochester method.

Manual English

When the vocabulary of the American Sign Language and fingerspelled words are presented in English word order, a 'pidgin' results. Pidgin Sign En-

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glish (PSE) is neither strictly English nor ASL, but combines elements of both.

A number of systems have recently been devised to assist deaf children in learning English. These systems supplement some ASL signs with invented signs that correspond to elements of English words (plurals, prefixes, and suffixes, for example). There is usually a set of rules for word (sign) formation within the particular system. These systems are generically known as manually coded English or manual English systems. The two most commonly used today are Signing Exact English and Signed English. While each of these systems was devised primarily for use by parents and teachers in the educational setting, many of the invented and initialized signs from their lexicons are filtering into the vocabulary of the general deaf community.

Oral Communication

This term denotes the use of speech, residual hearing, and speechreading as the primary means of communication for deaf people.

The application of research findings and technological advances through the years has led to refinements in the rationale for and approach to teaching speech to deaf children. Several findings are pertinent here. Deaf children may actually have functional residual hearing. The speech signal is redundant. Since it carries excess information, it is not necessary to hear every sound to understand a message. For language learning to be successful with deaf children (no matter what the educational approach), programs of early intervention must take place during the critical language-learning years of birth through 6. Hearing screening procedures that accurately detect hearing impairments in very young children make it possible to fit hearing aids and other amplification devices and to introduce auditory and language training programs as soon as the problem is detected.

Almost all auditory approaches today rely heavily on the training of residual hearing. The traditional auditory/oral approach trains the hearing impaired child to acquire language through speechreading (lipreading), augmented by the use of residual hearing, and sometimes vibro-tactile cues. The auditory/verbal approach (also called unisensory or acoupedic method) teaches children to process language through amplified residual hearing, so that language is learned through auditory channels.

Speechreading

Recognizing spoken words by watching the speaker's lips, face, and gestures is a daily challenge for all deaf people. Speechreading is the least consistently visible of the communication choices available to deaf people; only about 30 percent of English sounds are visible on the lips, and 50 percent are homophonous, that is, they look like something else. Try it for yourself. Look in a mirror and 'say' without voice the words 'kite,' 'height,' 'night.' You'll see almost no changes on your lips to distinguish among those three words. Then say the following three words—'maybe,' 'baby,' 'pay me.' They look exactly alike on the lips.

Some deaf people become skilled speechreaders, especially if they can supplement what they see with some hearing. Many do not develop great skill at speechreading, but most deaf people do speechread to some extent. Because speechreading requires guesswork, very few deaf people rely on speechreading alone for exchanges of important information.

Cued Speech

Cued Speech is a system of communication in which eight hand shapes in four possible positions supplement the information visible on the lips. The hand "cue" signals a visual difference between sounds that look alike on the lips—such as /p/, /b/, /m/. These cues enable the hearing impaired person to see the phonetic equivalent of what others hear. It is a speech-based method of communication aimed at taking the guesswork out of speechreading.

Simultaneous Communication

This term denotes the combined use of speech, signs, and fingerspelling. Simultaneous communication offers the benefit of seeing two forms of a message at the same time. The deaf individual speechreads what is being spoken and simultaneously reads the signs and fingerspelling of the speaker.

Total Communication

Total Communication is a philosophy which implies acceptance and use of all possible methods of communication to assist the deaf child in acquiring language and the deaf person in understanding.

Historically, proponents of particular systems have often been at odds with proponents of other systems or modes. There is increasing consensus that whatever system or systems work best for the individual should be used to allow the hearing impaired person access to clear and understandable communication.

Deaf Adults in Today's Society

The deaf adult population in the United States is composed both of individuals deaf since early childhood and individuals who lost their hearing later in life. People who were deafened as adults, or after the age of 18, are sometimes called post-vocationally deaf. Having already embarked on their careers, these people may have serious problems both personally and professionally adjusting to their hearing loss. People who were deafened prior to age 18 may have problems not only with English language skills, but also, because of fewer opportunities for interaction with hearing people in pre-work settings, they may be less well prepared for interpersonal relationships they encounter in the job market.

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Educational Institutions

Schools for deaf students have traditionally played an important role in advancing the welfare of deaf people through education of deaf students and public information efforts about the capabilities and accomplishments of deaf people. Two national institutions each have enrollments of over 1,000 deaf students.

Gallaudet University
800 Florida Ave. NE
Washington, DC 20002-3625

National Technical Institute for the Deaf
Rochester Institute of Technology
1 Lomb Memorial Drive
Rochester, NY 14623

For descriptions of the more than 100 postsecondary programs for deaf students at community colleges and technical schools around the country, order a copy of **College and Career Programs for Deaf Students** for $12.95 from:

College and Career Programs
Center for Assessment and Demographic Studies
800 Florida Ave. NE
Washington, DC 20002-3625

Special Devices for Deaf People

Technology and inventiveness have lead to a number of devices which aid deaf people and increase convenience in their daily lives. Many of these devices are commercially available under different trade names.

Telecommunications Devices for Deaf People (TDDs) are mechanical/electronic devices which enable people to type phone messages over the telephone network. The term TDD is generic and replaces the earlier term TTY which refers specifically to teletypewriter machines. Telecaption adapters, sometimes called decoders, are devices which are either added to existing television sets or built into certain new sets to enable viewers to read dialogue and narrative as captions (subtitles) on the TV screen. These captions are not visible without such adapters.

Signalling Devices which add a flashing and/or vibrating signal to the existing auditory signal are popular with hearing impaired users. Among devices using flashing light signals are door "bells," telephone ring signallers, baby-cry signals (which alert the parent that the baby is crying), and smoke alarm systems. Alarm clocks may feature either the flashing light or vibrating signal.

Some Special Services

Numerous social service agencies extend their program services to deaf clients. In addition, various agencies and organizations—either related to deafness or to disability in general—provide specific services to deaf people. Among these special services are the following:

Captioned Films for the Deaf
A loan service of theatrical and educational films captioned for deaf viewers. Captioned Films for the Deaf is one of the projects funded by the Captioning and Adaptations Branch of the U.S. Department of Education to promote the education and welfare of deaf people through the use of media. This branch also provides funds for closed-captioned television programs, including the live-captioned ABC-TV news.

Registry of Interpreters for the Deaf, Inc.
A professional organization, RID maintains a national listing of individuals skilled in the use of American Sign Language and other sign systems and provides information on interpreting and evaluation and certification of interpreters for deaf people.

State Departments of Vocational Rehabilitation
Each state has specific provisions for the type and extent of vocational rehabilitation service, but all provide vocational evaluation, financial assistance for education and training, and job placement help.

Telecommunications for the Deaf, Inc.
TDI publishes an international telephone directory of individuals and organizations who own and maintain TDDs (telecommunications devices for deaf people) for personal or business use.

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Revised by Loraine DiPietro, Director, National Information Center on Deafness, Gallaudet University

Suggested Readings

Davis, H. and Silverman, R.S., (1978). ***Hearing and Deafness*** (4th ed.) New York: Holt, Rinehart and Winston.

Freeman, R., Carbin, C.F. and Boese, R., (1981). ***Can't Your Child Hear? A Guide for Those Who Care About Deaf Children.*** Baltimore: University Park Press.

Gannon, J., (1981). ***Deaf Heritage.*** Silver Spring, MD: National Association of the Deaf.

Katz, L., Mathis, S.; and Merrill, E.C. Jr., (1978). ***The Deaf Child in the Public Schools: A Handbook for Parents of Deaf Children*** (2nd ed.). Danville, IL: Interstate Printers and Publishers.

Mindel, E.; and Vernon, M., (1971). ***They Grow in Silence: The Deaf Child and his Family.*** Silver Spring, MD: National Association of the Deaf.

Moores, D., (1987). ***Educating the Deaf: Psychology, Principles, and Practices*** (3rd ed.). Boston: Houghton Mifflin Co.

Ogden,P.; and Lipsett, S.,(1982). ***The Silent Garden: Understanding the Hearing Impaired Child.*** New York City: St. Martin's Press.

Schlesinger, H.; and Meadow, K. (1974). ***Sound and Sign: Childhood Deafness and Mental Health.*** Berkeley: University of California.

Spradley, T.S.; and Spradley, J.P. (1978). ***Deaf Like Me.*** Washington, DC: Gallaudet University Press.

Directory of Services

The April issue of the ***American Annals of the Deaf*** is a directory of the various programs and services for deaf persons in the United States. Copies of this reference may be purchased from:

American Annals of the Deaf
Gallaudet University
KDES, PAS 6
800 Florida Ave. NE
Washington, DC 20002-3625

Additional Information

If you have specific questions that were not answered by this fact sheet, please contact either the National Information Center on Deafness, Gallaudet University, Washington, DC 20002, or the National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910.

The National Information Center on Deafness (NICD) is a centralized source of information on all aspects of deafness and hearing loss, including education of deaf children, hearing loss and aging, careers in the field of deafness, assistive devices and communication with hearing impaired people.

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

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MISCONCEPTIONS ABOUT PERSONS WITH HEARING IMPAIRMENTS

MYTH ➢ Deafness is not as severe a disability as blindness.	**FACT** ➢ Although it is impossible to predict the exact consequences of a disability on a person's functioning, in general, deafness poses more difficulties in adjustment than does blindness. This is largely due to the effects hearing loss can have on the ability to understand and speak oral language.
MYTH ➢ It is unhealthy for people who are deaf to socialize almost exclusively with others who are deaf.	**FACT** ➢ Many authorities now recognize that the phenomenon of a Deaf culture is natural and should be encouraged. In fact, some are worried that too much mainstreaming will diminish the influence of the Deaf culture.
MYTH ➢ In learning to understand what is being said to them, people with hearing impairment concentrate on reading lips.	**FACT** ➢ *Lipreading* refers only to visual cues arising from movement of the lips. Some people who are hearing impaired not only read lips, but also take advantage of a number of other visual cues, such as facial expressions and movements of the jaw and tongue. They are engaging in what is referred to as *speechreading*.
MYTH ➢ Speechreading is relatively easy to learn and is used by the majority of people with hearing impairment.	**FACT** ➢ Speechreading is extremely difficult to learn, and very few people who are hearing impaired actually become proficient speechreaders.
MYTH ➢ American Sign Language (ASL) is a loosely structured group of gestures.	**FACT** ➢ ASL is a true language in its own right with its own set of grammatical rules.
MYTH ➢ ASL can convey only concrete ideas.	**FACT** ➢ ASL can convey any level of abstraction.
MYTH ➢ People within the Deaf community are in favor of mainstreaming students who are deaf into regular classes.	**FACT** ➢ Some within the Deaf community have voiced the opinion that regular classes are not appropriate for many students who are deaf. They point to a need for a critical mass of students who are deaf in order to have effective educational programs.
MYTH ➢ Families in which both the child and the parents are deaf are at a distinct disadvantage compared to families in which the parents are hearing.	**FACT** ➢ Research has demonstrated that children who are deaf who have parents who are also deaf fare better in a number of academic and social areas. Authorities point to the parents' ability to communicate with their children in ASL as a major reason for this advantage.

Discrimination is a common problem for minority groups. Deaf people as members of a minority group, experience their share of discrimination. Deaf people as a group are **underemployed.** Together with members of other minority and disabled groups, deaf people are working to change attitudes which have given them jobs but inadequate advancement opportunities.

In the United States, deaf people work in almost every occupational field. Some have become doctors, dentists, lawyers, and members of the clergy. A number of deaf people enter careers within the field of deafness. Thirteen hundred teachers of deaf students in the United States are themselves hearing impaired individuals. In addition, there are deaf administrators, psychologists, social workers, counselors, and vocational rehabilitation specialists. Deaf people drive cars and hold noncommercial pilot's licenses and pursue the same leisure time interests as everyone else.

Many deaf young people have attended school with deaf classmates. This educational pattern, coupled with ease of communication and compatibility encouraged by shared experiences as deaf individuals, leads to socializing with other deaf individuals in maturity. Many deaf people (80 percent) tend to marry other deaf people; most of their children (approximately 90 percent) are hearing.

The Deaf Community

Because the problem in dealing with the hearing world is one of communication, deaf people tend to socialize together more than do people with other disabilities. However, members of the deaf community have contacts with other people, too. Some are active members of organizations of hearing people. Some deaf people move freely between hearing and deaf groups, while other deaf people may have almost no social contact with hearing people. A few deaf people may choose to socialize only with hearing people.

While it is possible to find deaf individuals in every section of the United States, there are major concentrations of deaf people in the larger metropolitan areas of the East and West coasts.

Organizations of and for Deaf People

Clubs and organizations of deaf people range in purpose from those with social motives (watching captioned films, for example) to those with charitable aims. Organizations offer deaf people the opportunity to pursue a hobby (athletics, drama) or civic commitment (political action) on the local, regional or national level. Local or state associations of deaf people may be affiliated with the National Association of the Deaf. The Oral Deaf Adults Section of the Alexander Graham Bell Association for the Deaf has local chapters that provide social opportunities for deaf people who favor oral communication. The National Fraternal Society of the Deaf provides insurance and supports social and charitable functions. It has 120 divisions throughout the United States and Canada.

A few of the more than 20 national organizations of and for deaf people in the United States are briefly described in the following list. Many of these organizations publish newsletters, magazines, or journals. Add to these the publications developed by clubs and schools for the deaf (for students and alumni) and it is possible to identify 400 publications aimed at a readership within the deaf community.

Alexander Graham Bell Association for the Deaf
3417 Volta Place, NW
Washington, DC 20007
(202) 227-5220 (V/TDD)

A private, nonprofit organization serving as an information resource, advocate, publisher, and conference organizer, the Alexander Graham Bell Association is committed to finding more effective ways of teaching deaf and hard of hearing people to communicate orally. Sections within the organization focus on the needs of deaf adults (Oral Deaf Adults Section) and parents (International Parent Organization).

American Deafness and Rehabilitation Association
P.O. Box 55369
Little Rock, AR 77225
(501) 663-4617 (V/TDD)

An interdisciplinary organization for professional and lay persons concerned with services to adult deaf people, ADARA sponsors workshops for state rehabilitation coordinators.

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400 (V/TDD)

Composed of parents and concerned professionals, ASDC provides information, organizes conventions, and offers training to parents and families with children who are hearing impaired.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788 (V/TDD)

With 50 state association affiliates and an aggregate membership exceeding 20,000, the NAD is a consumer advocate organization concerned about and involved with every area of interest affecting life opportunities for deaf people. It serves as a clearinghouse of information on deafness, offers for sale over 20 books on various aspects of deafness, and works cooperatively with other organizations representing both deafness and other disabilities on matters of common concern.

P TO THE CHALLENGE

by Steve Lewis

Deaf pitcher doesn't let disability stand in way of success

Hitters and pitchers look for them. Catchers and coaches give them. Everyone tries to steal them. Signs are as much a part of the game of baseball as the bat and ball.

And in a society that does not always accommodate the hearing impaired, baseball—with its endless parade of signs and gestures—is an oasis where the hearing and deaf alike attend on equal footing.

Aaron Farley is deaf. He also happens to have been raised on baseball. The name given at birth—Aaron (as in Hank) Matthew (as in Eddie, only without the 's') Farley (as in Aaron's father Bob, big Braves' fan)—left little doubt that baseball would constitute a huge part of his life.

Make no mistake about it, when Farley takes the mound in this weekend's 17-18 year old Babe Ruth state tournament in Purcellville, the 18-year-old C.B. Baker all-star will be just another baseball player.

"Baseball is one of those beautiful sports that rely so much on symbols," said Bob Farley, who also serves as all-star coach. "When the game starts we all speak a different language, anyway."

If baseball is unique in that sense, then it owes a good deal to deaf individuals such as William Hoy. An act so central to the national pastime—the umpire's animated strike call—was prompted by Hoy, a turn-of-the-century National League outfielder, who required hand signals to know if the pitch was a ball or a strike.

The symbolic code that has developed in the years since is a language Farley probably understands better than most.

Born profoundly deaf—the most severe degree of hearing impairment—Farley is capable of hearing high-decibel sounds like thunder, but little else. So he compensates with eyes. Farley confidently states that no one on the playing field sees as much as he does. His father doesn't remember him ever missing a sign.

His own safety, in fact, requires that Farley rigidly adhere to the proverbial command—keep your eye on the ball.

"He has to focus and concentrate on the entire game," said the elder Farley. "I don't know if it makes him better, but it sure makes him tired."

Moreover, it makes him intensely competitive. As one not distracted on the field, he expects nothing less from his teammates. "I don't want to make a mistake, I don't want my teammates to make a mistake," Aaron said. "I want to win."

Win he has. During the C.B. Baker regular season, Farley posted a perfect 4-0 record for champion Ruritan, the best mark in the league. He was equally successful at the plate with a .360 batting average.

PROGRESS PHOTO BY MATT GENTRY

Aaron Farley of the C. B. Baker League All-Star team has not let deafness keep him from enjoying success as a pitcher. The 18-year-old is 6–0 this summer (1992) in regular season and tournament play.

In last weekend's District 5 tournament, Farley added two more wins—including Sunday's 12-6 championship victory—to help put the Charlottesville squad in today's first-round game against the District 7 champions.

On the subject of stats, try this one: 3.60. Not ERA, but GPA. In June, Farley graduated with honors from Charlottesville High School and will attend Rochester (N.Y.) Institute of Technology this fall with plans to major in computer science and math.

A message blackboard in Farley's bedroom frequently carries this admonition from his father: "Most limitations are self-imposed." The son has taken the saying to heart. Consequently, Aaron Farley has not allowed his disability to get in the way of on- or off-field achievement.

He rejects the notion, however, that he is any sort of role model, but the message is clear: Being deaf is no excuse not to participate, or succeed.

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X. Speech and Language Disorders

- General Information about Speech and Language Disorders (NICHCY Fact Sheet)
- Misconceptions about Persons with Communication Disorders
- The Manual Alphabet
- Practice Learning Signs

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
1-800-695-0285 (Toll Free) (202) 416-0300 (Local, Voice/TT)
*SpecialNet User Name: NICHCY ** SCAN User Name: NICHCY*

General Information About

SPEECH AND LANGUAGE DISORDERS

Definition

Speech and language disorders refer to problems in communication and related areas such as oral motor function. These delays and disorders range from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech and feeding. Some causes of speech and language disorders include hearing loss, neurological disorders, brain injury, mental retardation, drug abuse, physical impairments such as cleft lip or palate, and vocal abuse or misuse. Frequently, however, the cause is unknown.

Incidence

One quarter of the students served in the public schools' special education programs (almost 1 million children in the 1988-89 school year) were categorized as speech or language impaired. This estimate does not include children who have speech/language problems secondary to other conditions such as deafness. Language disorders may be related to other disabilities such as mental retardation, autism, or cerebral palsy. It is estimated that communication disorders (including speech, language, and hearing disorders) affect one of every 10 people in the United States.

Characteristics

A child's communication is considered delayed when the child is noticeably behind his or her peers in the acquisition of speech and/or language skills. Sometimes a child will have greater receptive (understanding) than expressive (speaking) language skills, but this is not always the case.

Speech disorders refer to difficulties producing speech sounds or problems with voice quality. They might be characterized by an interruption in the flow or rhythm of speech, such as stuttering, which is called dysfluency. Speech disorders may be problems with the way sounds are formed, called articulation or phonological disorders, or they may be difficulties with the pitch, volume, or quality of the voice. There may be a combination of several problems. People with speech disorders have trouble using some speech sounds, which can also be a symptom of a delay. They may say "see" when they mean "ski" or they may have trouble using other sounds like "l" or "r". Listeners may have trouble understanding what someone with a speech disorder is trying to say. People with voice disorders may have trouble with the way their voices sound.

A language disorder is an impairment in the ability to understand and/or use words in context, both verbally and nonverbally. Some characteristics of language disorders include improper use of words and their meanings, inability to express ideas, inappropriate grammatical patterns, reduced vocabulary, and inability to follow directions. One or a combination of these characteristics may occur in children who are affected by language learning disabilities or developmental language delay. Children may hear or see a word but not be able to understand its meaning. They may have trouble getting others to understand what they are trying to communicate.

Educational Implications

Because all communication disorders carry the potential to isolate individuals from their social and educational surroundings, it is essential to find appropriate timely intervention. While many speech and language patterns can be called "baby talk" and are part of a young child's normal development, they can become problems if they are not outgrown as expected. In this way an initial delay in speech and language or an initial speech pattern can become a disorder which can cause difficulties in learning. Because of the way the brain develops, it is easier to learn language and communication skills before the age of 5. When children have muscular disorders, hearing problems or developmental delays, their acquisition of speech, language, and related skills is often affected.

Speech-language pathologists assist children who have communication disorders in various ways. They provide individual therapy for the child; consult with the child's teacher about the most effective ways to facilitate the child's communication in the class setting; and work closely with the family to develop goals and techniques for effective therapy in class and at home. Technology can help children whose physical conditions make communication difficult. The use of electronic communication systems allow nonspeaking people and people with severe physical disabilities to engage in the give and take of shared thought.

Vocabulary and concept growth continues during the years children are in school. Reading and writing are taught and, as students get older, the understanding and use of language becomes more complex. Communication skills are at the heart of the education experience. Speech and/or language therapy may continue throughout a student's school year either in the form of direct therapy or on a consultant basis. The speech-language pathologist may assist vocational teachers and counselors in establishing communication goals related to the work experiences of students and suggest strategies that are effective for the important transition from school to employment and adult life.

Communication has many components. All serve to increase the way people learn about the world around them, utilize knowledge and skills, and interact with colleagues, family, and friends.

Resources

Bernthal, J.E. & Bankson, N.W. (1993). *Articulation and phonological disorders* (3rd ed). Englewood Cliffs, NJ: Prentice Hall. (Telephone: 1-800-947-7700.)

Beukelman, D.R., & Mirenda, P. (1992). *Augmentative and alternative communication: Management of severe communication disorders in children and adults.* Baltimore, MD: Paul H. Brookes. (Telephone: 1-800-638-3775.)

Shames, G.H., & Wiig, E.H. (1990). *Human communication disorders: An introduction* (3rd ed.). Columbus, OH: Merrill. (Contact Macmillan Publishing at 1-800-257-5755.)

Organizations

Alliance for Technology Access
1128 Solano Avenue
Albany, CA 94706
(510) 528-0747

Cleft Palate Foundation
1218 Grandview Ave.
University of Pittsburgh
Pittsburgh, PA 15211
412-481-1376; 800-242-5338; 800-243-5338 (in PA)

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
301-897-5700 (V/TT); 800-638-8255

Learning Disabilities Association of America (LDA)
4156 Library Road
Pittsburgh, PA 15234
412-341-1515; 412-341-8077

Division for Children with Communication Disorders
c/o Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091-1589
703-620-3660

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
312-726-6200; 312-726-4258 (TT)
800-221-6827 (Calls outside IL)
(For information about services for children and youth.)

Scottish Rite Foundation
Southern Jurisdiction, U.S.A., Inc.
1733 Sixteenth Street, N.W.
Washington, DC 20009-3199
202-232-3579

Trace Research and Development Center
University of Wisconsin - Madison
S-151 Waisman Center
Madison, WI 53705-2280
608-262-6966; 608-263-5408 (TT)

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UPDATE 12/93

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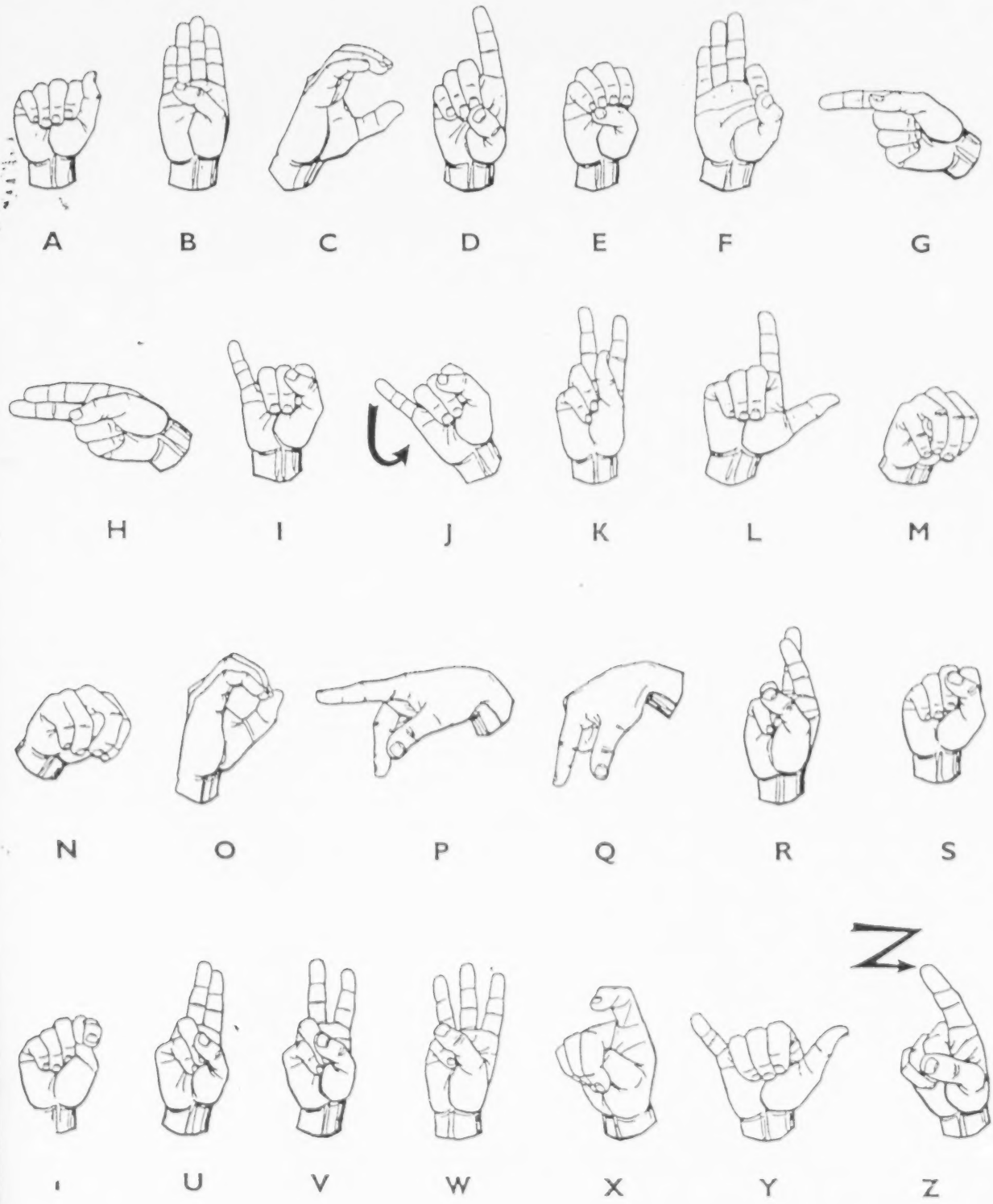
MISCONCEPTIONS ABOUT PERSONS WITH COMMUNICATION DISORDERS

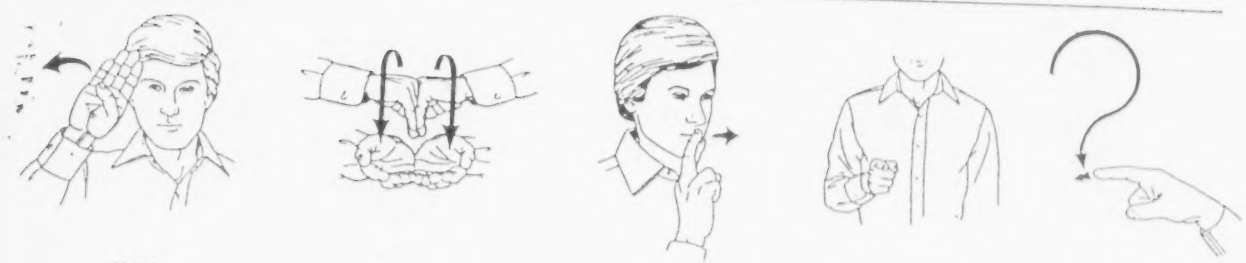
MYTH ➢ Children with language disorders always have speech difficulties as well.	**FACT** ➢ It is possible for a child to have good speech and yet not make any sense when he or she talks; however, most children with language disorders have speech disorders as well.
MYTH ➢ Individuals with communication disorders always have emotional or behavioral disorders or mental retardation.	**FACT** ➢ Some children with communication disorders are normal in cognitive, social, and emotional development.
MYTH ➢ How children learn language is now well understood.	**FACT** ➢ Although recent research has revealed quite a lot about the sequence of language acquisition and has led to theories of language development, exactly how children learn language is still unknown.
MYTH ➢ Stuttering is primarily a disorder of people with extremely high IQs. Children who stutter become stuttering adults.	**FACT** ➢ Stuttering can affect individuals at any level of intellectual ability. Some children who stutter continue stuttering as adults; most, however, stop stuttering before or during adolescence with help from a speech-language pathologist. Stuttering is primarily a childhood disorder, found much more often in boys than in girls.
MYTH ➢ Disorders of phonology (or articulation) are never very serious and are always easy to correct.	**FACT** ➢ Disorders of phonology can make speech unintelligible; it is sometimes very difficult to correct phonological or articulation problems, especially if the individual has cerebral palsy, mental retardation, or emotional or behavioral disorders.
MYTH ➢ A child with a cleft palate always has defective speech.	**FACT** ➢ The child born with a cleft palate may or may not have a speech disorder, depending on the nature of the cleft, the medical treatment given, and other factors such as psychological characteristics and speech training.
MYTH ➢ There is no relationship between intelligence and disorders of communication.	**FACT** ➢ Communication disorders tend to occur more frequently among individuals of lower intellectual ability, although these disorders may occur in individuals who are extremely intelligent.
MYTH ➢ There is not much overlap between language disorders and learning disabilities.	**FACT** ➢ Problems with verbal skills—listening, reading, writing, speaking—are often a central feature of a learning disability. The definitions of language disorders and several other disabilities are overlapping.

The Manual Alphabet

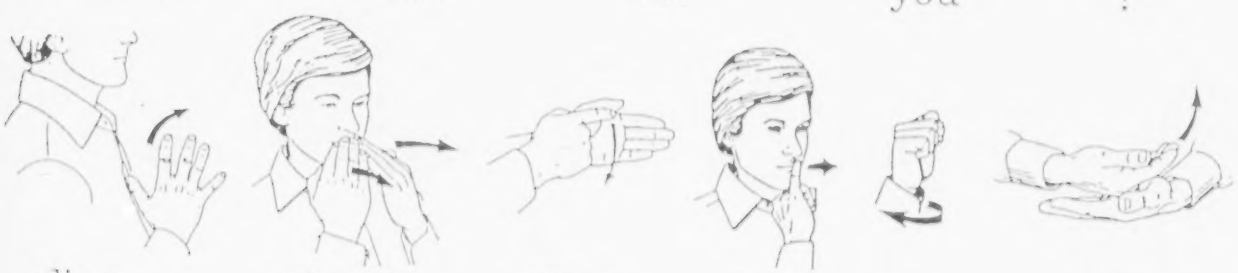


Practice Learning Signs

Learn and practice the signs and sentences on each page before proceeding to the next. Descriptions are supplied at the bottom of each page.



Hi,- how are you ?



Fine, thanks. What is the new

girl's / boy's / name?

XI. Autism

- General Information about Autism (NICHCY Fact Sheet)
- Common Misconceptions about Persons with Autism
- Autism Fact Sheet
- Autism, Mark Reber
- Facts about Autism
- Self Injury, Answers to Questions for Parents, Teachers and Caregivers
- Early Childhood Autism: Changing Perspectives

NICHCY

National Information Center for Children and Youth with Disabilities
P.O. Box 1492, Washington, D.C. 20013-1492
(703) 893-6061 (Local) (1-800) 999-5599 (Toll Free) (703) 893-8614 (TT)
SpecialNet User Name: NICHCY •• SCAN User Name: NICHCY

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

General Information About

AUTISM

NEW PHONE NUMBER:
(202) 416-0300 (VOICE/TT)

✧ Definition ✧

Autism is a developmental disorder which usually becomes evident before the age of three years. It is a neurological or brain disorder in which behavior, communication, and social interactions are the primary disabilities.

✧ Incidence ✧

The rate of incidence, or how often autism occurs in children, ranges from five to fifteen out of 10,000 births. The different estimates are based on slightly different definitions of autism.

It is three times more common in boys than girls and is rarely found in more than one child in a family.

Autism can be caused by a number of factors, but the cause in the vast majority is not known. It is known that autism is caused by biological, not psychological, factors.

✧ Characteristics ✧

Some babies show signs of autism from infancy. They may not like to cuddle and may show little interest in their families.

Typical characteristics of autism are often described as:

- difficulty relating to people, objects and events;
- repetitive movements such as rocking and spinning, head banging and hand twisting;
- insistence that the environment and routine remain unchanged;
- avoidance of eye contact;
- verbal and nonverbal communication skills are severely impaired;
- use of toys and objects is an unconventional manner, little imaginative play;
- severe impairment of social interaction development; and
- limited intellectual ability.

It should be noted that any one of these characteristics may occur in children with other disabilities. In these cases the term "autistic-like" behavior is used.

✧ Educational Implications ✧

Early diagnosis and educational evaluation of autism are very important, although help given at any age can make a significant difference.

Public Law 101-476, the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act, now includes autism as a separate disability category. Children with autism will be eligible for special education and related services under this new category.

Until recently, children with autism have been eligible for special education and related

services under the category of "other health impaired." The regulations (CFR 300.5) to the Education of the Handicapped Act state, "Other health impaired means (i) having an autistic condition which is manifested by severe communication and other developmental and educational problems...". These regulations will be changed to reflect autism as a category included under the IDEA.

Emphasis in education needs to be on helping the child to learn ways to communicate and on structuring the environment so that it is consistent and predictable. Effective teaching includes attention to behavior plans, positive behavior management, and clear expectations and rules.

Many of these methods can be developed in conjunction with parents and followed through at home. Continuity and consistency between home and school environments can greatly aid in the security and progress of persons with autism.

While autism is a lifetime condition, with special training, supervision, and support, many adults with autism can live and work in the community.

✧ Resources ✧

Autism Research International Newsletter
Institute for Child Behavior Research
4182 Adams Avenue
San Diego, CA 92116

Journal of Autism and Developmental Disorders
Plenum Publishing Corporation
233 Spring Street
New York, NY 10013

Park, Clara, (1982) *The Siege.* Boston; Little Brown and Company.

Powers, Michael D. (Ed) (1989). *Children with Autism, A Parent's Guide.* Rockville, MD; Woodbine House.

Wing, L., M.D., (1980). *Autistic Children: A Guide for Parents and Professionals.* Secaucus, NJ: The Citadel Press.

✧ Organizations ✧

Autism Hotline
Autism Services Center
101 Richmond Street
Huntington, WV 25702
(304) 523-8269

Autism Society of America
8601 Georgia Avenue
Suite 503
Silver Spring, MD 20910
(301) 565-0433

Institute for Child Behavior Research
4182 Adams Avenue
San Diego, CA 92116
(618) 281-7165

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UPDATE 5/92

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Common Misconceptions About Autism

Misconceptions	Facts
1. Autism is an emotional disorder	Autism occurs as a result of diverse organic etiologies
2. It is difficult to distinguish between autism and childhood schizophrenia	Autism and schizophrenia differ on several important features, including age of onset, cognitive level, course, and family history
3. Autism occurs more commonly among higher SES and educational levels	Autism appears to be evenly distributed across all SES and educational levels
4. Autism exists only in childhood	Autism is a lifelong disorder
5. With the proper treatment, most autistic children eventually "outgrow" autism	Characteristics and behaviors associated with autism often improve as a result of intervention
6. Autistic children do not show social attachments, even to parents	Autistic children can and do form social attachments, though their relationships typically lack a sense of reciprocity
7. Autistic children do not show affectionate behavior	Autistic children can and do show affectionate behaviors such as hugging and kissing
8. Most autistic children have special talents or abilities	Many autistic children have unevenly developed cognitive skills, but very few have savant capabilities
9. Most autistic children are not mentally retarded	70% - 80% of autistic children function intellectually within the range of mental retardation
10. Autistic children are more intelligent than scores from appropriate tests indicate	I.Q. scores are accurate, stable, and predictive when appropriate instruments and assessment strategies are used

W. Stone, Ph.D.
6/94

Is there a voluntary agency for autism?

Yes, The Autism Society of America, Inc. is the only national agency dedicated to the education and welfare of people with autism. Its priorities are research and education. More than 200 chapters exist across the United States. The Society's national office address is:

Autism Society of America
7910 Woodmont Avenue • Suite 650
Bethesda, Maryland 20814-3015
(301) 657-0881 • Fax: (301) 657-0869

*Formerly NSAC, The National Society for Children and Adults With Autism

How can I learn more?

The Information and Referral Service at the Autism Society of America, Inc. can provide reading lists and film lists, and will answer questions. Following are some recommended publications, which can be obtained through our national office along with a comprehensive list of other appropriate references.

Advocate, Autism Society of America, A Collection of Writings from *Advocate*, 1979-1989, Compiled by Beverly Bateman, Lincoln Nebraska

Alternatives to Punishment, Donnellan and LaVigna, Irvington Publishers, Inc., 1986

Autistic Children, A Guide for Parents and Professionals, Wing, Citadel Press, 1972

Biology of the Autistic Syndromes, Mary Coleman, et al, Amsterdam, North Holland Publishing Company, 1976

Children With Autism, Edited by Powers, 1989

Classic Readings in Autism, compiled by Ann Donnellan, New York, Teachers College Press, 1985

Current Issues in Autism Series, Edited by Schopler and Mesibov, Plenum Press

Emergence Labled Autistic, Grandin, Arena Press, 1986

Gentle Teaching, McGee, Menolascino, Hobba, Menolascino, Human Sciences Press, Inc., 1987

Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior, Rimland, 1964

Mixed Blessings, Christopher and Christopher, Abingdon Press, 1989

The Siege, Park, Boston: Little Brown & Co. 1982

Note: Much of the information in this leaflet is taken from the Short Definition of Autism, adopted by the Professional Advisory Board and the Board of Directors of the Autism Society of America, Inc., June 27, 1977

AUTISM:

Not responsive to normal teaching methods
Inappropriate laughing and crying
No understanding of real dangers
Apparent insensitivity to pain
Resistant to being held
Seeks and enjoys isolation; plays alone; exhibits physical withdrawal
Avoids eye contact
Shows affection clumsily
Difficulty in expressing needs; may get pointers
Inappropriate attachments to objects
Echoes words and phrases
Inappropriate response, or no response to sound
Extreme distress for no discernible reason
Spins objects or self
Does not play well with other children
Resists changes in routine
Physically aggressive or passive

NOTE: persons with autism may possess the above characteristics in various combinations and in varying degrees of severity.

Autism Society of America
7910 Woodmont Avenue • Suite 650
Bethesda, Maryland 20814-3015
(301) 657-0881 • Fax: (301) 657-0869

*Formerly NSAC, The National Society for Children and Adults With Autism

Prepared by
Office of Scientific and Health Reports
National Institute of Neurological and Communicative Disorders and Stroke
Bethesda, Maryland 20205

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Reprinted February 1983, 1987, 1990, 1991

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

FACT SHEET

autism

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What is autism?

Autism is a severely incapacitating, lifelong developmental disability that begins at birth or during the first 3 years of life. It occurs in approximately 5 of every 10,000 births. The incidence is three times greater if a broader definition of autism is used. In the broader category would be both people with classical autism and others with varying degrees of autistic behavior. Autism is three times more common in males than females, and has been found throughout the world in families of all racial, ethnic, and social backgrounds.

What are the symptoms of autism?

- Slow development or lack of physical, social, and learning skills.
- Immature rhythms of speech, limited understanding of ideas, and use of words without attaching the usual meaning to them.
- Abnormal responses to sensations. Sight hearing, touch, pain, balance, smell, taste, the way a child holds his body—any one or a combination of these responses may be affected. (See illustrations on back panel)
- Abnormal ways of relating to people, objects and events.

Approximately 60% of all those with autism have IQ scores below 50, 20% between 50 and 70, and 20% greater than 70. Most show wide variations in performance on different tests at different times. Many children with autism have distinct skills in music, mathematics, or in using spatial concepts (for example, working jigsaw puzzles), but manifest severe retardation in other areas.

What causes autism?

There appear to be several possible causes, either alone or in combination with others. Among these are untreated phenylketonuria, rubella, cerebral disease, and chemical exposure in pregnancy. Biochemical imbalance and genetic predisposition have also emerged as possible causes. Non-known factors in the

psychological environment of a child have been shown to cause autism.

How is it diagnosed?

Because there are no medical tests for autism at present, the diagnosis must be based on observations of the child's behavior. Sometimes the process of elimination is the only guide. For older children, whose early symptoms have changed, it may be necessary to interview the parents about the child's early years in order to avoid misdiagnosis.

Is autism ever associated with other disorders?

Autism occurs either by itself or in association with other disorders which affect brain function. Perinatal viral infections, some metabolic disturbances, epilepsy, or mental retardation may result in, or exist in conjunction with autistic behavior.

How severe can autism be?

In milder forms, autism most resembles a learning disability such as childhood aphasia. Usually, however, people with autism are substantially handicapped.

With approximately 3% of those afflicted, severe autism may cause extreme forms of self-injurious, repetitive, highly unusual, and aggressive behavior. The behavior may persist and be very difficult to change, posing a tremendous challenge to those who must manage, treat, and teach individuals with autism.

People with autism live normal life spans. Since certain symptoms may change or even disappear over time, persons with autism should be reevaluated periodically and their treatment adjusted to meet their changing needs.

What are the most effective treatments?

Various methods of treatment have been tried but no single treatment is effective in all cases. However, appropriate programming, based on individual functioning level and need, is of prime importance. There is no known cure.

Education. Highly structured, skill-oriented training, tailored to the individual, has proven most helpful. Social and language skills should be developed as much as possible. Thought must also be given to avoiding secondary handicaps, such as loss of muscle tone when inactivity is a problem.

Counseling. Supportive counseling may be helpful for families with members who have autism, just as it is for other families with members who have lifelong disabilities. Physicians can usually advise parents as to counseling services available. Care must be taken to avoid unenlightened counselors who erroneously believe that parental attitudes and behavior cause autism.

Medication/Diet. In the types of autism where metabolic abnormalities can be identified, controlled diet and/or medication can be beneficial. Examples are those whose autism is caused by an excess of uric acid in the blood, or whose autism is aggravated by nutritional imbalances. Also, properly monitored medication to decrease specific symptoms can help some autistic individuals live more satisfactory lives.

What research is being done?

The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) initiated a research section on autism in 1983, and may be contacted directly concerning research initiatives in diagnostic, treatment, educational, habilitative, and evaluative approaches relevant to autism.

NINCDS is continuing to study the 14 autistic children identified in its Collaborative Perinatal Project (a 15-year study of 55,000 pregnancies and the outcomes). This project centers on efforts to identify predictive signs of autism.

Ongoing study is necessary to determine how autism occurs and to identify ways to prevent or alleviate its effects. Basic research in a broad spectrum of scientific disciplines is needed to shed further light on the challenges presented by Autism.

Chapter 22

Autism

with Mark Reber

Upon completion of this chapter, the reader will:
—be able to define autism
—understand the characteristics of this disorder
—know how to distinguish autism from other developmental disabilities
—be acquainted with the various intervention approaches to this disorder

Like mental retardation, autism is a brain-based developmental disability with multiple causes. Autism differs from mental retardation in that its characteristic feature is not a delay in development, but a series of striking deviations from normal developmental patterns that become apparent by 3 years of age. Autism involves disturbances in cognition, interpersonal communication, social interactions, and behavior (in particular, the presence of obsessional, ritualistic, stereotyped, and rigid behaviors) (American Psychiatric Association, 1987; Cohen, Donnellan, & Paul, 1987; Gillberg, 1990). Deviant development in all of these areas is necessary for a diagnosis of autism, thus giving rise to its classification as a pervasive developmental disorder.

Autism is a rare condition. Studies have determined its prevalence to be about 4 in 10,000 (Lotter, 1966; Ritvo, Freeman, Pingree, et al., 1989), and boys with autism outnumber girls 4:1. There appears to be a genetic component, as a family with one child with autism has about a 9% risk of having a second child with autism (Ritvo, Jorde, Mason-Brothers, et al., 1989).

A HISTORICAL PERSPECTIVE

Despite its rarity, autism has been the focus of considerable research since it was first described in 1943. Dr. Leo Kanner published the first description of what he called "autistic disturbances of affective contact" (Kanner, 1943, p. 217). He identified a group of children who exhibited symptoms that isolated them from their environment

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Table 22.1. Diagnostic criteria for autism

At least 8 of the following 16 items should be present. The child should exhibit at least two items from Group A, one from Group B, and one from Group C. (The examples are arranged so that those first mentioned are more likely to apply to younger children or children with more severe autism, and the later examples are more likely to apply to older children or children with less severe autism.)

Group A

Qualitative impairment in social interaction as manifested by the following:

1. Marked lack of awareness of the existence of others or their feelings
2. No effort or an abnormal effort to seek comfort at times of distress (e.g., does not come for comfort even when ill, hurt, or tired); seeks comfort in a stereotyped way (e.g., says "cheese, cheese, cheese" whenever hurt)
3. No imitation or impaired imitation (e.g., does not wave bye-bye, does not copy mother's domestic activities, mechanically imitates others' actions out of context)
4. No social play or abnormal social play (e.g., does not actively participate in simple games, prefers solitary play activities, involves other children in play only as "mechanical aids")
5. Gross impairment in ability to make peer friendships (e.g., no interest in making peer friendships; lacks understanding of conventions of social interaction [e.g., reads telephone book to uninterested peer])

Group B

Qualitative impairment in verbal and nonverbal communication and in imaginative activity as manifested by the following:

1. No mode of communication
2. Markedly abnormal nonverbal communication (e.g., does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, stares fixedly in social situations)
3. Absence of imaginative activity (e.g., no playacting of adult roles, fantasy characters, or animals; lack of interest in stories about imaginary events)
4. Marked abnormalities in speech production, including volume, pitch, stress, rate, rhythm, and intonation (e.g., monotonous tone, question-like melody, high pitch)
5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (e.g., immediate echolalia, mechanical repetition of television commercial); use of "you" when "I" is meant (e.g., using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (e.g., "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (e.g., starts talking about train schedules during a conversation about sports)
6. Markedly impaired ability to initiate or sustain conversations with others, despite adequate speech (e.g., lengthy monologues on one subject regardless of interjections from others)

Group C

Markedly restricted repertoire of activities and interests as manifested by the following:

1. Stereotyped body movements (e.g., hand flicking, hand twisting, spinning, head banging, complex whole-body movements)
2. Persistent preoccupation with parts of objects (e.g., sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (e.g., insists on carrying around a piece of string)
3. Marked distress over changes in trivial aspects of environment (e.g., when a vase is moved from usual position)
4. Unreasonable insistence on following routines in precise detail (e.g., insisting that exactly the same route be followed when shopping)
5. Markedly restricted range of interests and a preoccupation with one narrow interest (e.g., aligning objects, amassing facts about meteorology, pretending to be a fantasy character)

Adapted from American Psychiatric Association (1987).

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autism demonstrate extreme aloofness and total indifference to other people. The second component, impaired social communication, is characterized by an absence of pleasure in the exchange of smiles and feelings (i.e., body language). This characteristic may be obvious as early as the first 2–3 months of life, though it often goes unrecognized until other deficits become more obvious (Stone, Lemanek, Fishel, et al., 1990). Impaired social communication also implies a lack of desire to communicate with others or communication that is limited to the simple expression of needs. The third component, impaired social imagination and understanding, refers to the inability to imitate others and engage in pretend play or to imagine another's thoughts and feelings. For example, infants with this deficit do not copy their mothers' facial expressions.

Other social deficits associated with autism include not seeking comfort when hurt and lacking interest in forming friendships. It is unclear whether children with autism do not display normal attachment behavior or do not understand relationships well enough to form them (Hertzig, Snow, & Sherman, 1989; Shapiro, Frosch, & Arnold, 1987; Sigman & Mundy, 1989).

Communication Disorders

In children with autism, the development of language is severely delayed and deviant, hindering both expressive and receptive communication (Ferrari, 1982). Cooing and babbling may develop normally in the first 6 months of life, but then may regress. Speech may develop late or not at all. About half of children with autism remain mute throughout their lives and may even be unable to use gestures or signs to communicate (Rutter, 1985a). Those who develop language do not use it creatively or spontaneously. Their voices are often high-pitched, with unsual speech rhythm and intonation, which makes their speech sound sing-song or monotonous. They tend to use language in a very stereotyped, rote fashion, exhibiting excellent memorization skills but actually communicating very little, if any, meaning. They tend to repeat phrases and long commercial jingles. While it may seem that they are understanding what they are saying, they are usually parroting what they have heard. Despite good articulation and an adequate vocabulary, these children have a severe expressive language disorder.

Receptive language is affected as well. Children with autism may respond to brief phrases, but they find it very difficult to understand more complex commands. They learn better with visual than with auditory cues. At one point, language deficits were thought to be the primary cause of social withdrawal in children with autism, but these deficits are now regarded as secondary to the brain abnormality that causes the more fundamental disorder in relating to other people (Paul, 1987). Development of language is an important prognostic feature in autism. Children who develop language fare much better than those who do not (Schreibman, 1988).

Behavior Problems

The behavior problems in autism, particularly the restricted behavior repertoire and diminished response to environmental change, are among the most striking features of

the disorder. Obsessive rituals and strict adherence to routines are common; including, for example, rigid insistence in eating at the same time every day and eating a restricted menu of foods, sitting in exactly the same position at the table, placing objects in a particular location, and touching every door knob one passes. Young children with autism may show intense attachment to unusual objects, such as a piece of plastic tubing, rather than a cuddly item like a teddy bear. They may not use toys in their intended manner, but focus instead on a part of a toy, such as the wheels on a toy truck, which they may spin incessantly. A common form of play is to line objects up in rows. Shining surfaces, rotating fans, and people's hair or beards may fascinate these young children. Older, more cognitively advanced individuals may become intensely preoccupied with train schedules, calendars, or particular patterns of numerical relationships. They will focus on these things to the exclusion of other activities.

Frequently, children with autism become upset and have intense tantrums if anything interferes with these rituals and preoccupations. Similar tantrums may be provoked by trivial departures from daily routines or changes in the environment. Stereotyped movements and self-stimulating behaviors, such as rocking, hand waving, arm flapping, toe walking, head banging, and other forms of self-injurious behavior are also common, especially among children with autism who have low IQs (Howlin & Rutter, 1987).

Other behavior problems associated with autism include sleep disturbances (especially in younger children), short attention spans, hyperactivity, tantrums, and aggressiveness. These behaviors, while not specific to autism, may be as difficult to manage as the characteristics of autism.

Intellectual Functioning

Children with autism function at various levels in the intellectual spectrum. However, about 70% have mental retardation: 35% have mild retardation, 15% have moderate retardation, and 20% have severe or profound retardation. Twenty-five percent fall in the borderline-to-normal range of intelligence (IQ 70–100) and about 5% have IQs over 100 (Minshew & Payton, 1988).

Psychological testing can be performed on children with autism, and the resultant IQs appear to be fairly accurate, providing the testing is done by a psychologist who is experienced in working with such children. The tests may need to be adapted, or nonverbal tests may be needed because the performance of children with autism is uneven. They tend to perform better on tests of visual-spatial skills and rote memory, and poorer on tasks requiring symbolic and logical reasoning. Some children with autism have restricted areas of higher functioning, called *islets of ability* or *splinter skills*. These include musical skills, such as perfect pitch, exceptional rote memory, an unusual capacity for jigsaw puzzles, or the ability to do rapid calculations of a specific kind, such as finding the day of the week for distant dates. Usually, these splinter skills relate to the individual's selected area of preoccupation and do not help them to solve problems in daily life. Even if the splinter skill involves some useful function, the child with autism is often not able to apply the skill to real life events.

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with autism than in the general population. Taken together, these studies indicate a genetic predisposition to autism.

DISTINGUISHING AUTISM FROM OTHER DEVELOPMENTAL DISABILITIES

Since intervention strategies vary according to diagnosis, it is important to distinguish autism from other developmental disabilities. The most common disorders that are mistaken for autism are mental retardation, childhood psychosis, sensory impairments, developmental language disorders, and progressive nervous system disorders.

Autism is distinguished from mental retardation by its characteristic social and behavior problems and by a somewhat different pattern of cognitive deficits. Children with autism shun social interactions and treat everyone, even parents, as objects; children with mental retardation generally enjoy social contact. Children with mental retardation usually have equal delays in language, cognitive, and visual-perceptual skills, whereas children with autism have more prominent language impairments. However, most children with autism also have mental retardation, and many individuals with severe mental retardation display autistic features, such as stereotyped movements and self-injury (Capute, Derivan, Chauvel, et al., 1975).

Autism may also be confused with psychiatric disorders, such as schizophrenia (American Psychiatric Association, 1987). The key difference between the two syndromes is age of onset. Autism begins in the first 3 years of life, while schizophrenia rarely starts before adolescence. Furthermore, while the child with autism may behave in a bizarre manner, he or she will not have the delusions and hallucinations that are characteristic of schizophrenia. In addition, while a child with autism lacks imagination, a child with schizophrenia may live in a fantasy world. Finally, children with schizophrenia do not usually have mental retardation (see Chapter 23).

Children with sensory impairments may also demonstrate autistic features. Children with visual impairment often display self-stimulatory behaviors and lack the skills necessary for interpersonal interactions. They do not have the global language disorder that distinguishes children with autism, and their intelligence is usually normal. Furthermore, if there is improvement in their sensory function, the autistic features disappear. This makes it extremely important for the vision and hearing of children with autistic behaviors to be tested before the diagnosis of autism is confirmed.

Similarly, children with developmental language disorders may display shyness, echolalia, and some social withdrawal (see Chapter 19), but they typically do not show the deviant language features of autism, such as stereotyped utterances, abnormal social interactions, bizarre behaviors, and absence of a desire to communicate (Rutter, 1985a).

Finally, a group of progressive neurological diseases initially may be misdiagnosed as autism. Children with these disorders develop normally in infancy, then start to lose both intellectual and motor skills, and fall behind (Menkes, 1990). One example is Rett syndrome (Hagberg, Aicardi, Dias, et al., 1983; Percy, Zoghbi, Lewis, et al., 1987). Although children with autism may also seem to regress in their development, their loss of skills is usually restricted to language. Furthermore, most children with

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... social development that can be traced to the first year of life. The diagnosis of a progressive neurological disorder becomes evident as abilities continue to deteriorate over time.

Testing for Autism

There is no specific medical test for autism. Blood tests and EEGs may be abnormal, but are nonspecific. However, tests may be conducted to identify syndromes commonly associated with autism and to rule out other explanations for abnormal behavior. For example, a chromosome study would be performed if fragile X syndrome is suspected (see Chapter 16); metabolic studies might be ordered to test for PKU or other inborn errors of metabolism; and an MRI scan may be done to ... for abnormalities in the cortex or cerebellum.

TREATMENT AND INTERVENTION APPROACHES

Michael Rutter, an eminent British child psychiatrist, has outlined five main goals of the treatment of autism: 1) the fostering of normal development, 2) the promotion of learning, 3) the reduction of rigidity and stereotypy, 4) the elimination of nonspecific maladaptive behaviors, and 5) the alleviation of family distress (Rutter, 1985b).

These goals are best met through a comprehensive educational and behavior ... program that includes a highly structured education setting, language training, behavioral interventions, positive social experiences, and intensive parent involvement (Howlin & Rutter, 1987; Rogers & Lewis, 1989; Schreibman, 1988). Treatment should begin as early as possible, as there is some evidence that early intervention to promote ... sition of communication skills can lessen later maladaptive behaviors (Prizant & Wetherby, 1988).

Behavior therapy may be needed to modify behaviors that might otherwise interfere with development and learning. Reduction in stereotypical, rigid, ritualistic, and maladaptive behaviors (e.g., tantrums, aggression, self-injury) may be accomplished through a number of behavioral strategies. For example, behavior shaping can help to systematically positively reinforce approximations of desired communicative behavior and withdrawal of reinforcement can help to extinguish self-stimulatory behaviors. Other behavioral interventions attempt to increase social interaction (Schreibman, 1988). Parents are often used as co-therapists in these forms of intervention.

Fostering normal development must include language therapy with an emphasis ... pragmatics of language (i.e., using it to accomplish social goals) (Schuler & Prizant, 1987). Interactive and meaningful conversations should be modeled and practiced, and echolalia discouraged. With children with autism who are mute, attempts should be made to train verbal utterances, such as babbling or jargoning (Howlin & Rutter, 1987; Schuler & Prizant, 1987). Sign language can also be attempted, but it is often difficult for children with autism to learn. A novel approach, termed *facilitated communication*, is now being evaluated. The basic element of facilitated communication is providing physical support to the child's arm as he or she attempts to type messages on a keyboard or communication board (Biklen, 1990).

This is done to overcome dyspraxia that may underlie the child's inability to use a communication device independently. Art and music therapy have also been used in attempts to communicate with children with autism nonverbally.

The education of children with autism usually requires highly structured programs with predictable routines and presentation of material in graded steps (Rogers & Lewis, 1989; Rutter, 1985a). Children with autism should be enrolled in preschool early intervention programs that stress communication skills and social interactions. By school age, many children with autism learn effectively in public school special education classes with children who function at similar developmental levels. Class sizes should be small, and activities should be broken into simple subunits to hold the children's interest and decrease stereotypical behavior. One-to-one interactions with teachers and fellow students are encouraged so that children with autism may develop social skills. Higher functioning children with autism may be integrated into regular education settings.

Medications play a limited role in the treatment of autism, as there is no pharmacological remedy for the disorder (Minshew & Payton, 1988). Certain medications, however, have been used to relieve some of the symptoms, including hyperactivity, irritable mood, social withdrawal, and aggression. The best studied of these medications is haloperidol (Haldol), a high-potency antipsychotic drug that has been shown to be effective in decreasing stereotypical behaviors, withdrawal, aggression, negativism, and irritability, as well as increasing performance on learning tasks (Anderson, Campbell, Grega, et al., 1984; Joshi, Capozzoli, & Coyle, 1988). Unfortunately, haloperidol is also associated with a high incidence of movement abnormalities (Perry, Campbell, Adams, et al., 1989). A medication that once looked promising in autism, fenfluramine, has more recently been shown to be largely ineffective. In addition, it interferes with discrimination learning and is poorly tolerated (Campbell, Adams, Small, et al., 1988; Stern, Walker, Sawyer, et al., 1990; Varley & Holm, 1990). Opiate antagonists, such as naltrexone, are being studied to see if they alleviate any of the hyperactive and maladaptive behaviors associated with autism. Preliminary reports show mild benefits (Campbell, Anderson, Small, et al., 1990).

Stimulants, used to treat hyperactivity, were formerly thought to aggravate stereotyped behaviors. But, methylphenidate (Ritalin) has been shown to be helpful in controlling hyperactivity in some children with autism (Birmaher, Quintana, & Greenhill, 1988; Strayhorn, Rapp, Donina, et al., 1988). Clonidine (Catapres), a newer medication for hyperactivity, which was developed to treat hypertension in adults, may also be useful for treating hyperactivity in children with autism. Lithium has also been used to treat the manic-like symptoms of autism (Steingard & Biederman, 1987).

Parents need emotional support and advocacy and, most of all, should be brought into the treatment process as teachers and co-therapists of their children. There is no doubt that having a child with autism is enormously stressful for the family. In addition to the normal stresses of having a child with disabilities, there are many additional demands as well as the frustration of caring for a child who provides few emotional rewards, requires intense supervision, has disturbed sleep, and ex-

habits behavior that is difficult to manage. If emotional problems arise, family counseling is indicated.

KENNY: A CHILD WITH AUTISM

Kenny had problems from infancy. His early development was delayed, and his parents were quite concerned that Kenny would have mental retardation. They noticed that he did not "coo" or respond to sounds. He did not reach out to be picked up, and he seemed stiff and uncomfortable when they held him. Soon, his motor development improved. He sat by 8 months and walked by 15 months. His parents became hopeful that he did not have "brain damage." He also showed good visual perceptual skills, being able to put together simple puzzles by 2 years of age and to build intricate block towers by 2½.

Yet, his parents remained concerned about his language, behavior, and relationships with other people. At 2 years of age, he neither spoke nor consistently followed 1-step commands. He was a loner. He showed no interest in playing with other children and barely acknowledged his parents. He still did not like to be held. Kenny exhibited no warmth and maintained no eye contact with others. He had many strange, ritualistic behaviors. He spun around, rocked, and constantly played with a string. He would fly into a rage when the furniture was moved or when he encountered new situations.

By 4 years of age, Kenny had developed some language, but it was very strange. He had an extraordinary memory for numbers and commercials. He would constantly carry a detergent bottle around the house singing its advertising jingle, and he would endlessly repeat strings of numbers. However, he still basically communicated with no one. He could not follow 2-step commands and spoke in only 1- or 2-word phrases. More often than not, he pointed to what he wanted.

At this time, psychological testing was performed. Kenny's IQ was 37, indicating he functioned around the level of an 18-month-old. However, he could build block towers and solve puzzles at a 4-year-old level. Because of his strange behavior, withdrawal, and reactions of rage, he was referred to a child psychiatrist. These symptoms, combined with good gross motor and visual-perceptual skills and severe mental retardation, led to a diagnosis of autism. His parents, in a sense, were relieved; they had a diagnosis, some place to start.

Even more important, Kenny was enrolled in an intervention program. He received the drug haloperidol to decrease his anxiety. His reactions of rage decreased. He entered a special school program where language and other reasoning skills were taught at an 18-month-old level. Behavior management techniques were used to help Kenny with new social situations and to reduce self-stimulatory behavior. At the same time, Kenny's parents received counseling from a social worker and followed through on a behavior management program set up by a behavioral psychologist.

By 6 years of age, Kenny had improved substantially. He could now form 3-word sentences, and the automatic repetition of words decreased. His behavior was better, and he could be brought into new situations without difficulty.

Kenny's eventual outcome is still unclear. He will continue to gain new skills, but his cognitive function will likely remain in the range of mental retardation. It is hoped that he will gain increased communication and social skills that will permit him to function in supported employment when he is an adult.

PROGNOSIS

Autistic features generally become less pronounced as the child grows, and stereotypic behavior decreases. By adolescence, the child's function will principally depend on his or her intelligence and speech skills. Only about one-half of children with autism gain socially useful speech, usually by 5 years of age (Rutter, 1985a). The child with autism and moderate-to-severe mental retardation will function in a manner similar to other children with mental retardation, although he or she will have poorer language skills, possibly better problem-solving abilities, and a decreased interest in social interactions. Even among higher functioning individuals with autism, abnormalities of verbal expression, concrete thought processes, social awkwardness, and stereotyped and inappropriate social behaviors tend to persist (Wing, 1988). Overall, about 15% of children with autism have a good outcome, 15% a fair outcome, and 70% a poor outcome in terms of functioning independently in society as an adult. The majority live at home or in supervised living situations (Rumsey, Rapoport, & Sceery, 1985). Most individuals with autism are independent in self-care skills and can participate in activities of daily living (Wing, 1985). Some young adults can engage in supported employment, especially in jobs that require the use of their visual-motor skills. Those with normal intelligence can often live and work independently.

SUMMARY

Autism appears to be a distinct syndrome. Its principal characteristics are a global language disorder, abnormal behavior patterns, social isolation, and, usually, mental retardation. Its causes are many. Differentiation from other disabilities, such as mental retardation, psychiatric illness, sensory impairments, and progressive neurological disorders, is essential for proper therapy to be possible. Therapy consists of an interdisciplinary approach that includes psychiatry, speech-language pathology, behavioral psychology, and social work. At this point, the value of medication is uncertain. In adolescents and adults, the bizarre behavior is less apparent, but prognosis is generally poor. The children with the best hope for the future are those with the higher IQ scores.

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INSTITUTE ◆ *for*
the ◆ STUDY ◆ *of*
DEVELOPMENTAL
DISABILITIES

The University Affiliated Program of Indiana

FACTS ABOUT AUTISM

Indiana Resource Center for Autism

Indiana University

This document was developed and disseminated by the Indiana Resource Center for Autism (IRCA) located at the Institute for the Study of Developmental Disabilities (ISDD) at Indiana University, Bloomington. The ISDD is *the University Affiliated Program of Indiana*.

IRCA is one of four resource centers supported by the ISDD. IRCA's center operations are designed to complement the Institute's three core program center activities. The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services for individuals with disabilities across the life span. Institute activities include interdisciplinary training, technical assistance, reference information, and applied research.

If you are interested in obtaining further information on the ISDD contact:

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ISDD
2853 East Tenth Street
Bloomington, Indiana 47408-2601
Phone: (812) 855-6508
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FACTS ABOUT AUTISM

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c. 1991

WHAT IS AUTISM?

Autism is a diagnostic label for a lifelong developmental disability caused by a brain dysfunction.

- It occurs in approximately 1 in 1000 people of all races, cultures, and educational backgrounds.
- The disorder shows itself in infancy or early childhood.
- It is accompanied by mental retardation about 80% of the time.
- It can also occur with other conditions such as deafness, Down syndrome, Fragile X syndrome, and epilepsy.
- About four out of five people with autism are male.

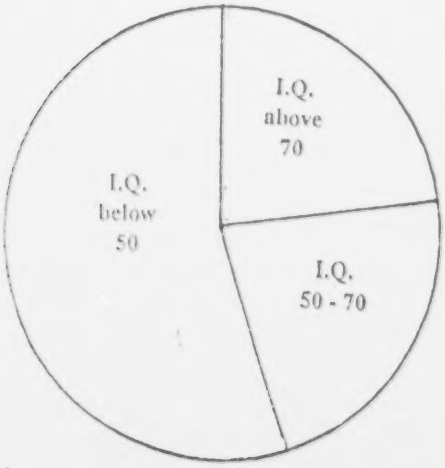
People with autism vary widely in abilities, intelligence levels, and behavioral characteristics. Across the spectrum of those diagnosed with autism, the common components are:

- Significant impairments in language and communication abilities,
- Significant impairments in social skills, and
- A limited number of activities and interests.

WHAT CAUSES AUTISM?

There is no single known cause for autism. Experts do not know exactly what is different about the structure, function, or chemistry of the brain in an individual with autism.

- Research is showing that the brain cells of people with autism work together in an unusual manner.
- The chemicals which carry messages between brain cells may also be too high or too low.
- Apparently, people with autism do not perceive or process incoming sensory information (hearing, sight, touch, smell, and movement) in the same way as other people.



Mental Retardation in People with Autism

People who have autism may also have other disorders such as. . .

mental retardation,
seizures,
genetic diseases,
cerebral palsy, or
brain malformations.

Autism, however, is a separate disorder aside from any other problems.

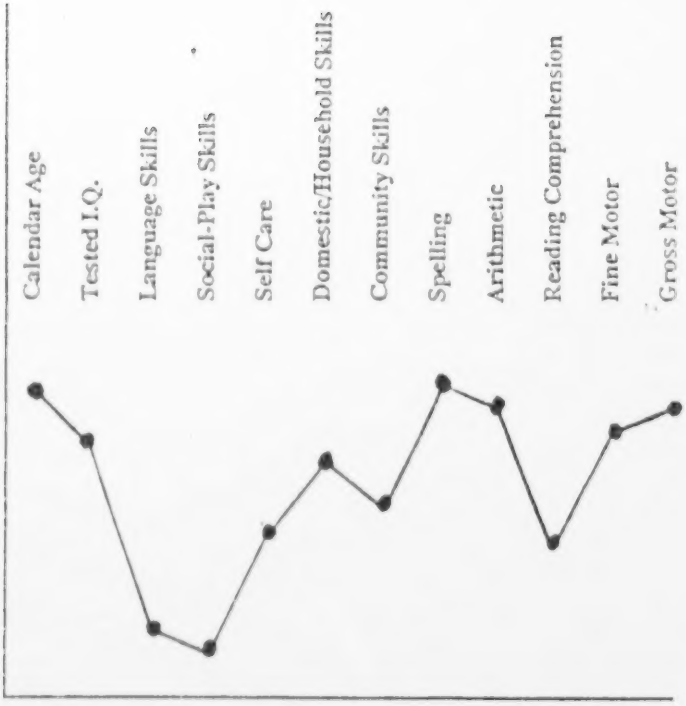
- There is no definite medical test which can diagnose autism.
- Genetic factors are considered to be one possible contributing cause of autism.
- In some families there seems to be a pattern of autism and/or associated problems of learning or language.
- Other causal factors being researched include viral infections during pregnancy, metabolic disorders, and birth complications.

HOW IS AUTISM DIAGNOSED?

The diagnosis of autism is best made on information compiled by various members of an interdisciplinary assessment team. Teams usually consist of a psychologist, a teacher, a speech/language pathologist, and a social worker. Other professionals such as a physical or occupational therapist, doctor, or nurse may be important additions to the team.

It is important that the team gather developmental and behavioral information from the family and school/program. A markedly uneven developmental pattern alerts the team to the possibility of autism. An early history of language delay and problems in the development of toy play, play with peers, pretend play, and odd use of eye contact in interactions with adults are other possible indicators.

Another characteristic often seen in autism is abnormal reactions to sensory stimuli. For example, people with autism may mouth or smell items in preference to looking at them or may become very upset when they hear a particular noise or see a particular object.



Sample Developmental Profile of a Person who is More Able and has Autism

In most individuals with autism these problems are most apparent between ages 3-6, but continue through the school years and into adulthood.

Individuals with autism who are more able (those with IQs over 70) may seem to have hyperactivity or a learning disability. But they also have significant social and communication problems which continue throughout their lives.

WHAT CAN HELP A CHILD WITH AUTISM?

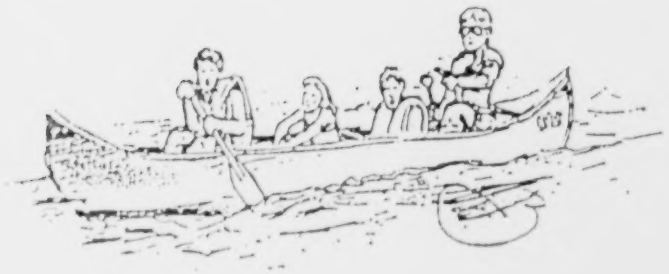
Children with autism need to be identified early. Families and teachers can then communicate and teach more effectively in ways that the child can understand, before the child, family, and school staff become very frustrated.

Children with autism need an individualized learning program. The emphasis needs to be on helping the child learn ways to communicate and on arranging the environment so that it is more consistent and predictable.

Children with autism need chances for successful experiences including reinforcement for small steps forward.

They need learning activities which incorporate their strengths and interests. The learning activities need to be functional and have a clear purpose that can eventually be understood by the child with autism.

They need planned integration with peers who are following the typical developmental pattern.



Most children with autism learn best through visual means. Teaching with objects and pictures, and providing peers to imitate helps them learn.

They also learn best through participation in real situations, since skills taught in isolation may not be remembered when the person with autism tries to use them in the real world.

Some children can benefit from medication if it is given for a specific problem such as anxiety, hyperactivity, depression, or other interfering behaviors. Family and doctor can work together to assess the child's need for medication. However, there is no medication that cures autism.

WHAT CAN HELP THE FAMILY OF A PERSON WITH AUTISM?

The family will need a comprehensive, coordinated, and flexible system of family supports throughout the lifetime of the person with autism.

The family needs information and knowledge about autism. Help and understanding of extended family members and friends will be an important support to the family.

An accepting and educated community as well as parent and sibling support groups may be helpful to families.

The family might need help in structuring daily living and teaching self care skills, such as bathing, dressing, eating, toileting, and sleeping. They might need help in planning and carrying through successful community and family outings.

The family often feels more successful if they can learn some specific behavioral strategies for their child with autism because it quickly becomes apparent that traditional disciplinary techniques are not successful with these children.

Families may need a coordinator/ advocate to help them access the best services in schools and other community facilities. This person might be a case manager from a state agency, a social worker at the agency where the person is enrolled in a program, an advocate from another service program, or a friend.

Unfortunately, there are presently few identifiable resources to help families obtain the needed information and support at home. Too much depends on the resourcefulness of each family.

Professional supports may include, but are not limited to:

- Respite in or out of the home. This help should be provided by a trained and knowledgeable person who can baby-sit or can help implement a program to teach the individual a specific skill or activity.

- Crisis intervention.

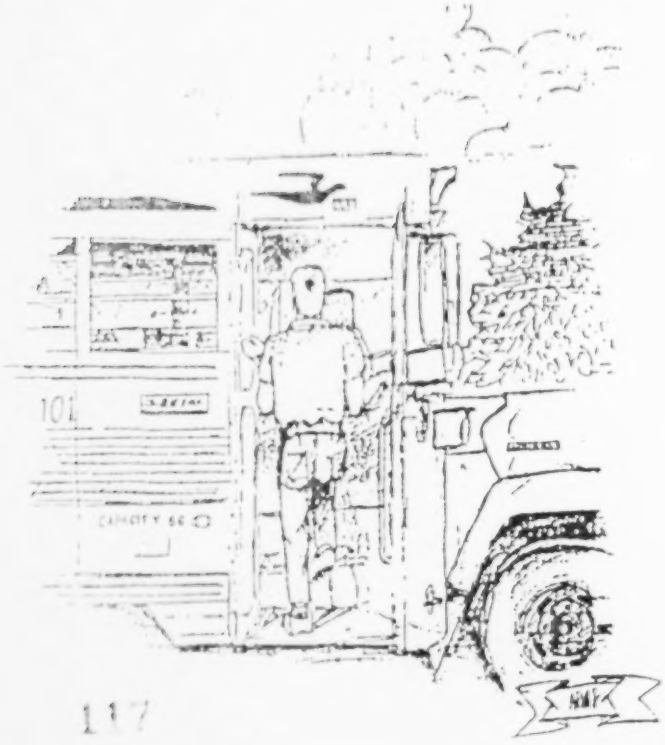
- Behavioral, speech, recreational, occupational, or other therapies.

WHAT HAPPENS TO A CHILD WITH AUTISM IN THE PUBLIC SCHOOLS?

Once the diagnosis of autism has been made, autism should be listed on the Individualized Education Plan (IEP).

From the child's first years in school, long term planning to promote independent functioning should be considered when choosing IEP goals.

A knowledgeable and caring advocate for the student will contribute towards a successful experience in the school system.



Placement or assignment to a specific program or combination of programs must be made on the basis of the individual student's strengths and needs.

Class placement could range from regular education full or part time with supports to programs for students with other types of handicapping conditions, mild or severe.

A combination of placements may be used if this best meets the student's needs, again depending on the student's Individual Educational Plan.

For most students with autism, speech/ language therapy will be required.

Often the curriculum will be centered on functional skills, skills that will enable the student to live as competently as possible as an adult. These functional skills may be part of a community-based program to learn job, social, and leisure skills. Students can practice social and language skills as well as learn by doing while participating in actual community settings.

A Vocational Rehabilitation Counselor must become involved in the student's educational planning in the last four years of school.

Special education districts may elect to permit students to continue their education until they are 21 years old.

WHAT HAPPENS TO AN ADULT WITH AUTISM?

Children with autism grow up to become adults with autism. However, research indicates that early identification and individually designed educational programs can help prepare and assist the person with autism to lead a meaningful and productive life.

Adults with autism will continue to learn. Their strengths, interests, and skills may change with schooling, other programs, or interventions. However, they will continue to have deficits in communication and social skills and to exhibit a restricted number of interests.

Planning for the adult years must begin early. During the school years, projections for living arrangements, job training, and leisure skills must be made by the family with input from professionals working with the child. Schooling should then be tailored towards building a foundation for all aspects of the person's adult life.

Adults with autism may live at home, with roommates in group homes or apartments that are supervised, or alone in homes or apartments with minimal supports. A few live completely independently. A very few marry and live with spouses.

A small percentage, who do not have mental retardation, attend college with support.

A high percentage of people with autism are receiving training ranging from daily living skills and sheltered work to training and placement in supported work through developmental disability agencies.

Adults with autism continue to have a restricted repertoire of recreational interests. They need help to attend concerts, sports events, or church, and to use libraries, swimming pools, and other community facilities of their choice.

They continue to benefit from individualized exercise activities, such as swimming, bowling, and bike riding, that they can share with others in the community. They usually like to continue their involvement in the community through shopping, eating out, and other daily living activities, often with family, friends, and co-workers.

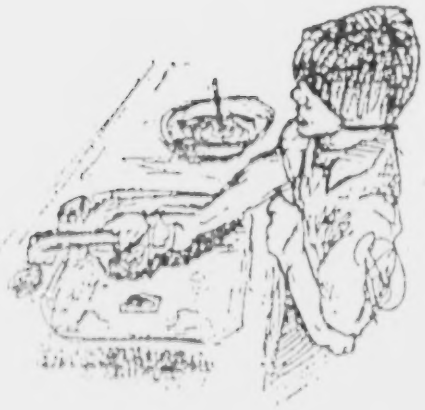
A few adults with autism drive. Other adults can learn to use public transportation; some depend on family or caregivers for mobility in the community.

WHAT JOBS CAN PEOPLE WITH AUTISM DO?

Some adults work at regular jobs in their community, often with some support from job coaches or supervisors. Other work in sheltered workshops.

People with autism, regardless of their functioning level, need certain supports built into employment and job training.

- They need a job which emphasizes their strengths and likes.
- They often need the job tasks organized and structured for them to minimize decision making.
- Written or pictured schedules and check lists can help organize job tasks and split a large job into several simpler steps.



Some examples of jobs people with autism are doing include library work, computer data entry, computer programming, janitorial/cleaning work, kitchen work such as dishwashing and basic meal preparation, assembly and packaging, office work, newspaper delivery, and yard care.

People with autism need jobs which are predictable but not necessarily repetitive. Skills for communication, social interaction, and independence are essential for success in the workplace.

Most people with autism will need specific job training and an understanding supervisor who can help problem solve and run interference when issues or problems of a communicative, social, or sensory nature arise at the work place.

SELF-INJURY

Answers to Questions for Parents, Teachers, & Caregivers

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The University of Minnesota's Institute for Disabilities Studies, directed by Travis Thompson, Ph.D., was established in 1987 to conduct basic and applied scientific research on preventing and intervening in developmental disabilities, and to design treatment and educational methods for people with disabilities. The Institute's research focuses on the prevention of disabilities arising from poverty; on behavioral and emotional problems associated with disabilities; and on disabilities that occur later in life. Because no single field of study can solve the complex problems of developmental disabilities, the Institute for Disabilities Studies is dedicated to interdisciplinary collaboration, making it a unique program within the University of Minnesota and across the country.

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Institute for Disabilities Studies,
University of Minnesota

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One in five people with mental retardation injures her or himself, causing pain and suffering to themselves, their families and others around them. This guide for parents, teachers and other caregivers of people who have developmental disabilities describes the more common types of self-injury and discusses methods for identifying causes. Interventions are discussed and information is provided concerning sources for further assistance.

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CHARACTERISTICS OF SELF-INJURY

What is self-injurious behavior and how common is it?

Self-injurious behavior (SIB) is repetitive behavior that causes physical harm. Usually the behavior takes a very similar form every time it occurs -- for example, one child may bruise the side of her head by hitting herself with the knuckles of one hand. Another may repeatedly bite one place on his right wrist. SIB is different from suicidal behavior and suicidal gestures, and is seen almost exclusively in people with mental retardation and other developmental disabilities. In most instances, self-injury can be successfully treated, especially by intervening early in the development of the problem. While self-injury is rarely life-threatening, without treatment it can sometimes worsen to the point of causing permanent damage. A few people with severe self-injury blind themselves or suffer hearing loss, destroy parts of their bodies (e.g., portions of fingers or lips), produce concussions, or cause repeated damage which leads to lingering infections.

Do all children who bump their heads or hit themselves develop the problem of self-injury?

No. About 17% of infants without a disability periodically hit their heads against their cribs or occasionally hit their head or face with their hand when they are tired or frustrated. Nearly all non-disabled infants stop hurting themselves by the time they are two years old. But as many as one in five children with mental retardation continue hurting themselves periodically for months and years, sometimes severely.

My four year old son slaps his face repeatedly, but he doesn't leave any bruises, just reddened skin. Is this a problem?

Face slapping or any other behavior that is performed often enough or intensely enough to cause reddening or breaking of the skin, bruises, bleeding, or other signs of tissue damage should be discussed with a professional experienced with self-injurious behavior in people with developmental disabilities. Sources of help include special education teachers, pediatricians, behavior analysts, social workers, child psychiatrists and psychologists, and pediatric neurologists.

Do children with some particular disabilities have more problems with self-injury than children with other disabilities?

Children with several uncommon disabling conditions, such as Autism, Cornelia de Lange syndrome, Fragile X syndrome, Lesch-Nyhan syndrome, and Rett syndrome have problems with self-injury more often than children with other developmental disabilities. However, since as many as 20% of children with disabilities display self-injury at some time in their lives, the problem extends well beyond these rarer disabilities. People wishing further information about specific disabilities often associated with self-injury should contact the resources listed at the end of this brochure.

CAUSES OF SELF-INJURY

What is known about the causes of the problem?

Thirty years ago, some writers speculated that children who hurt themselves were born the same as other children but that their self-injury resulted from a cold or detached style of mothering. There is no evidence to support this theory.

Today, most experts realize that self-injury usually has more than one cause. There may often be an underlying biological tendency for a child to self-injure. How often, under what circumstances and how intensely the child self-injures often depends on learning experiences, which can cause the self-injury to decrease or sometimes grow much worse.

Can medical problems cause self-injurious behavior?

Several medical conditions can lead to self-injury. Children with ear infections, for example, may try to reduce their discomfort by hitting or slapping at their ears. Similarly, they may repeatedly scratch at an area of itching skin, and continue to scratch when the skin begins to heal. Once the earache or skin irritation clears up, the self-injury usually stops. If the self-injury continues after the medical problem is over, another cause for the behavior should be considered.

Can dietary factors such as sugar, artificial coloring, or other food additives cause self-injury?

There is little carefully done research on the effects of diet or food ingredients on self-injury, or on megavitamin therapy as a treatment for self-injury. The studies on food and hyperactivity (extreme restlessness and overactivity) in children show no consistent effect of diet on behavior. For most children, activity level does not appear to be changed by the items in a normal diet, but a small number of children may be affected by diet.

I often see my child hurting himself when he is angry. For example, he bumps his head when it is time to put on his shoes. Why does he do this?

Children sometimes learn to avoid or delay doing things that they don't like by hurting themselves. Perhaps the youngster finds it difficult to put on his shoes, or does not enjoy the activity that will follow once he is dressed. Maybe he just prefers to continue with whatever he is doing. Because it is

difficult for adults to continue to request something from a child who is engaged in self-injury, some children learn to control what happens in their lives by hurting themselves. Self-injury is especially likely to be learned if the child cannot speak and has no other effective way to communicate.

My child speaks only a few words. Is it possible that she is trying to tell us something by hurting herself?

Self-injury can be an effective method for getting attention from adults, because the parent's natural response is to immediately go to the child to see what is wrong and to try to stop the self-injury. Sometimes it is necessary for adults to physically prevent the child from injuring him or herself. Children who have difficulty communicating can learn that attention can be gotten at any time by hurting themselves. Beyond simply gaining attention, children can also learn to hurt themselves to obtain other things they need or want. These may include preferred foods, favored activities, or being left alone. Self-injury is disturbing and even alarming to adults, and they will do whatever they can to stop it. Adults often offer various things to the child until s/he stops self-injuring. Unfortunately, the child may self-injure for a different reason the next time, and the process of adult guessing will be repeated again and again, unless a more satisfactory form of communication is developed.

Even though our child communicates very well, he threatens to scratch his face or hurts himself in other ways when he wants something he shouldn't have. Since he tells us exactly what he wants, communication can't be the reason for his self-injury.

Self-injury can still be a powerful and quick way for a child to get what he wants, at least part of the time. Seeing children deliberately hurt themselves is extremely upsetting for parents and others. It is very difficult not to give in at least occasionally, and provide what the child wants to stop the self-injury. Although it is not intended, this rewards the child's self-injury and can cause the self-injury to continue.

So far, none of this seems to fit my child. She has Down syndrome, and had a complete medical evaluation showing no medical problems that could account for her self-injury. It doesn't seem to be an attempt to communicate or to get attention. In fact, she likes to be alone. She rocks for long periods of time. When she rocks, she bumps against the wall and has caused a bruised spot that seems never to heal.

Some children perform a repetitive movement that results in skin, muscle, or even bone damage because it is repeated over and over again. The stimulation produced by the repeated movement may be pleasant to her, much as rocking is enjoyed by a baby. The injury is a by-product of the way the movement is performed (in this case, by constantly bumping against the wall). Similar problems are seen in children who have impaired vision. A child with a visual handicap might learn to press a finger into the eye because of the flashes of light this mechanical stimulation produces through the optic nerve. Obviously, this can cause physical damage to the eye.

I can see that repeating the same movement can cause injury as an accidental by-product of the movement. However, when my son bangs his head, it seems that his only purpose is to damage himself.

A different kind of self-stimulation can result from self-injury: Sufficient pain causes the release of "endogenous opioids," which are natural chemicals in our bodies that protect us from feeling intense pain. Endogenous opioids can also produce feelings of euphoria, such as the so-called "runner's high" that some people experience when running marathons. Some people may self-injure in order to be stimulated by these pleasant effects of endogenous opioids. Research on endogenous opioids as a cause of self-injurious behavior is just beginning, and may lead to new treatments for some self-injury.

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TREATMENTS FOR SELF-INJURY

With so many different causes, how is self-injury treated?

The first step is to try to discover the causes of the child's self-injurious behavior. It is important to identify any medical problems that might be responsible. This requires a thorough examination by a physician familiar with children with mental retardation. Other causes for self-injury can be identified by examining the circumstances in which the child self-injures. When the behavior occurs primarily in adult company but rarely when the child is alone, it is often directed at getting attention or other things that the child needs or wants. Self-injury that occurs when the child is asked to do something or during activities the child dislikes may be attempts to avoid unpleasant activities. The child who is just as likely to self-injure when alone as when he or she is with adults may be showing behavior that is a form of self-stimulation. Each of these causes suggests a different avenue of treatment to a professional experienced in treating self-injury.

Once causes are identified, what treatments are available?

A range of treatments are available, including providing more rewarding activities at which the youngster can easily succeed, providing communication training, decreasing the demands made on a child, and drug treatment. A positive environment with appropriate training, social, recreational, and other experiences must provide the foundation for any treatment for self-injury. That environment must provide activities with the correct amount of challenge: Tasks should be easy enough for the child to be successful. Assessing the environment of a self-injurious child, and selection and use of effective treatments, usually require the assistance of a developmental disabilities professional. Treatments should be matched to the cause identified. For example, children who learn to hurt themselves to gain attention from parents, teachers or other people caring for them can usually be

taught to seek that attention in healthier ways, making it unnecessary for them to hurt themselves. Teaching children to develop other communication methods, or to use other constructive ways of gaining adult attention is often enough to reduce self-injury. In other circumstances, self-injury is thought to be caused mainly by a biological condition, such as a brain chemical imbalance. In such instances, it may be necessary to treat the underlying problems with a drug intended to correct the imbalance.

My child takes medication for self-injury. She still hurts herself, but not as often.

Medications are currently one of the most common forms of treatment for self-injury. The medications usually tried for self-injury are called neuroleptics, which are the same types of drugs used for treating some major mental illnesses. These and other drugs can be helpful for certain conditions, however they are rarely used alone except when the person clearly has mental illness as well as mental retardation. A disadvantage of some drug treatments is that they can have both immediate and long-term unwanted side effects, some of which can be very serious. Treatment with medication always requires consultation with a physician.

Some friends have suggested that I spank my daughter for self-injury. Is this a good idea?

No. Positive, non-aversive interventions are usually sufficient to reduce or eliminate self-injurious behavior, and parents are urged not to use spanking, slapping, or scolding to control self-injury. Punishment procedures by themselves are not an appropriate treatment. However, as one part of a carefully designed overall treatment program in closely supervised clinical settings, various response suppression procedures have been reported to be effective under some circumstances. Such procedures are controversial. Parents wishing further information on this topic are encouraged to contact the following resources:

1) The position statement on the use of aversive and deprivation procedures of the Association for Retarded Citizens Minnesota (ARC MN). This statement is available by calling ARC MN at (800) 582-5256 or (612) 827-5641, or from the Institute for Disabilities Studies, (612) 627-4537. Addresses for both organizations are listed among the resources at the end of this brochure.

2) The 1989 National Institutes of Health Consensus Development Conference Statement, *Treatment of Destructive Behaviors in Persons with Developmental Disabilities*. Single copies can be obtained from the Director of Communications, Office of Medical Applications of Research, National Institutes of Health, Building 1, Room 260, Bethesda, MD 20892.

When my child is busy, there seems to be less self-injury.

Whether at home or at school, keeping a child occupied with enjoyable activities at which they can easily succeed, and providing frequent adult attention will often reduce self-injury. The key to reducing self-injury by providing these activities is to promote the child's active responding and learning of new skills. It appears that it is most helpful to have the child participate in doing things, rather than doing things to or for the child.

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FOR MORE INFORMATION ABOUT SELF-INJURY

This brochure was produced by the Institute for Disabilities Studies, a program of the University of Minnesota, and was written by Bruce L. Bakke, Ph.D. Support was provided by The Minneapolis Foundation. This material provides an introduction to the problem of self-injurious behavior in people with developmental disabilities. Further information can be obtained by contacting the Institute or the people and organizations listed below:

Institute for Disabilities Studies
Technical Assistance Program
University of Minnesota
2221 University Avenue Southeast, Suite 145
Minneapolis, MN 55414
(612) 627-4537, or FAX (612) 627-4522

Association for Retarded Citizens Minnesota (ARC MN)
3225 Lyndale Avenue South
Minneapolis, MN 55408
(612) 827-5641, or toll free (800) 582-5256

Nonaversive Behavior Management Information & Referral Service
National Research & Training Center on Community-Referenced, Nonaversive Behavior Management for Students with Severe Disabilities
San Francisco State University
San Francisco, CA 94132
Toll-free (800) 451-0608 (9 AM to 4 PM Pacific Time)

Michael F. Cataldo, Ph.D.
Director of Psychology
The Kennedy Institute
The Johns Hopkins University
707 North Broadway
Baltimore, MD 21205
(301) 550-9455

For information on a specific syndrome, please contact:

Twin Cities Society for Children & Adults with Autism (TSAC)
253 East Fourth Street
St. Paul, MN 55101
(612) 228-9074

Cornelia de Lange Syndrome Foundation
60 Dyer Avenue
Collensville, CT 06022
(203) 693-0159, or toll free (800) 223-8355

Lesch-Nyhan Syndrome
William L. Nyhan, M.D., Ph.D.
Professor of Pediatrics
School of Medicine
University of California - San Diego
San Diego, CA 92093-0609
(619) 534-4150

National Fragile X Foundation
1441 York Street, Suite 215
Denver, CO 80206
(303) 333-6155, or toll free (800) 688-8765

International Rett Syndrome Association
8511 Rose Marie Drive
Fort Washington, MD 20744
(301) 248-7031

Tourette Syndrome Association
42 - 40 Bell Boulevard
Bayside, NY 11361.
(718) 224-2999, or toll free (800) 237-0717

For general information about disabilities and caregiving:

PACER Center
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966, or FAX (612) 827-3065

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Early Childhood Autism: Changing Perspectives

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This article reviews current concepts and research findings concerning early childhood autism with an emphasis on recent changes in perspectives on the disorder. Autism is viewed as a pervasive developmental disorder with cognitive impairment as a central feature. The evolution of the current definition of autism is traced with reference to research findings that prompted revisions of the original definition. Evidence is summarized that demonstrates long-term cognitive dysfunction and supports a biogenic rather than psychogenic view of autism. Current psychological, educational, and biological interventions are evaluated. Available information on long-range adjustment in adolescence and adulthood is reviewed, along with variables in early life that are predictive of later functioning.

The past two decades have seen a new perspective on autism emerge. The once prevailing view of autism as a psychogenic emotional disorder has been gradually displaced by the concept of autism as a developmental disorder in which cognitive dysfunction plays a central role. This shift in perspective culminated in the 1979 title change of the *Journal of Autism and Childhood Schizophrenia* to the *Journal of Autism and Developmental Disorders* (Schopler, Rutter, & Chess, 1979) and the recent classification of autism as a pervasive developmental disorder by the *Diagnostic and Statistical Manual of Mental Disorders: DSM-III* (American Psychiatric Association, 1980). This developmental perspective has evolved out of cumulative research findings which show that: (a) autism is consistently associated with organic more than psychosocial variables (DeMyer, Hingtgen, &

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Jackson, 1981; Piggot, 1979; Rutter, 1979) and (b) cognitive impairment represents the primary and most enduring psychological handicap in autism (DeMyer et al., 1981; Morgan, 1984; Rutter, 1983).

This article focuses on some major shifts in thinking about autism that have occurred in recent years. These revisions in thinking have not only theoretical implications, but also relevance for those practitioners providing service to autistic children and adults. The changes center on the definition of autism, the nature of the basic impairment, and the relative contribution of biological versus psychosocial factors to the development of the disorder. These changes also address issues of treatment, educational, and vocational needs, as well as long-term prognosis.

Changes in Definition

The official history of autism began in 1938 when Leo Kanner, Director of the Child Psychiatry Clinic at Johns Hopkins, saw a 5-year-old boy from a small Mississippi town (Kanner, 1943, 1973). The boy demonstrated a novel cluster of behavioral symptoms that Kanner had never seen before nor read about in the literature. Although Kanner appreciated the uniqueness of the syndrome presented by this youngster, he could not have foreseen at that time the vast impact that this disorder would have on the behavioral sciences and the long-standing controversy that would surround it. By 1943, Kanner had seen 10 more children who presented this strange set of symptoms. That year, he published his now classic article that first described these children and proposed that their symptoms represented a rare behavior disorder (Kanner, 1943). The next year, he coined the term *early infantile autism* for the syndrome (Kanner, 1944).

Kanner (1943, 1949) outlined five major symptoms as composing the syndrome. First and foremost was the inability of these children to relate normally to people and situations from the start of life. Throughout infancy and childhood, they maintained what Kanner called "autistic aloneness," forming no apparent attachments to people and seeming to live in their own world, as if others did not exist. The second feature was the children's obsessive need to maintain sameness in the environment. The third characteristic was their failure to use language for the purpose of communication. The fourth was their fascination with objects, and their ability to handle them with dexterity. The fifth was their good "cognitive potentialities," as inferred from their attractive appearances and serious facial expressions, and the extraordinary skills demonstrated in certain isolated areas.

Despite the intensive scrutiny to which autism has been subjected over the years, Kanner's original behavioral syndrome has survived in fairly intact form. The recent revisions in definition relate more to his inferences about the disorder than to the behavior per se. One revision concerns Kanner's inference that autistic children have "good cognitive potentialities." Another change relates to the assumption that autistic children are neurologically intact. Recent definitions of autism, such as those offered by *DSM-III* (American Psychiatric Association, 1980) and the National Association of Autistic Children (Ritvo & Freeman, 1977), do not include normal intelligence and absence of neuropathology as criteria. Autism is now assumed to occur at all levels of intelligence with or without demonstrable organic pathology.

In *DSM-III*, which provides the most widely used set of diagnostic criteria for autism, the disorder is listed as a *pervasive developmental disorder*. Such disorders, which in the past had been called childhood psychoses, are characterized by marked distortions in the timing, rate, and sequence of many psychological functions. The six criteria for autism by *DSM-III* are:

> (a) onset before 30 months of age
>
> (b) pervasive lack of responsiveness to other people (autism)
>
> (c) gross deficits in language development
>
> (d) if speech is present, peculiar speech patterns...
>
> (e) bizarre responses to various aspects of environment (e.g., resistance to change, peculiar interest in or attachments to inanimate objects)
>
> (f) absence of delusions, hallucinations, loosening of associations, and incoherence as in schizophrenia
>
> (pp. 89-90)

Cognitive Impairment in Autism

The exclusion by *DSM-III* of any stipulation of normal cognitive functioning is based on longitudinal studies showing that most autistic persons reveal substantial cognitive impairment that persists throughout their lives. There is no longer any doubt that, in most cases, autism and mental retardation coexist (Schopler & Mesibov, 1983). Although the level of functional intelligence varies widely in autistic children, the vast majority function within the retarded range (Bartak & Rutter, 1976; DeMyer et al., 1974). About 60% of autistic children have IQs below 50; 20% have IQs between 50 and 70; and only 20% have IQs of 70 or higher (Ritvo & Freeman,

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1977). Further, the intellectual level remains stable throughout the lives of most autistic individuals (Rutter, Greenfeld, & Lockyer, 1967).

It is often stated that the mental retardation in autism is spurious, because the IQs obtained on autistic children are not representative of their "true" intelligence. The autistic child who obtained a low IQ or is "untestable" is often viewed as inaccessible, inattentive, and resistant to testing. No consistent evidence exists to support the argument that the generally low intellectual scores are more a function of negativism than cognitive impairment. Further, a number of studies have demonstrated that the "untestability" reflects low ability more than refusal to participate (Alpern, 1967; Alpern & Kimberlin, 1979; Hingtgen & Churchill, 1969, 1971). These studies reveal that valid measures of "untestable" autistic children can usually be obtained if the tests are not dependent on language and are commensurate with the child's developmental level.

Also reflective of a basic cognitive impairment is the language retardation found in the preponderance of autistic persons. A growing body of evidence points to language deficiency as a central feature of the disorder. At least 28% of those diagnosed autistic are mute (Lotter, 1967). Those who do develop speech show a wide range of individual differences in ability to communicate, with most demonstrating substantial retardation in language development (Bartak, Rutter, & Cox, 1975; Lord & Baker, 1977). The language defects usually appear at a very early age; in fact, speech delay represents the most frequent early complaint by parents of autistic children (Ornitz & Ritvo, 1976). The early deficits tend to persist; autistic children, regardless of age, generally perform well below expectations for age. The typical 6-year-old autistic child, for example, functions at or below the 3-year-old level on most language tests. Moreover, these language scores are usually well below developmental ages estimated from nonverbal performance tests (DeMyer, 1976; Lord & Baker, 1977).

The cognitive variables of language and IQ assume even greater importance in light of the finding that they represent the most potent predictors of the autistic child's eventual adjustment. Onset of meaningful speech before age 5 or 6 appears to be crucial to later adjustment (Kanner, 1971; Kanner, Rodriquez, & Ashenden, 1972; Lotter, 1978; Rutter, Greenfeld, & Lockyer, 1967). The child who develops functional speech by this age at least stands a chance to attain marginal or good adjustment, whereas the mute child has virtually no chance at all. The measured intelligence of the young autistic child also serves as a strong predictor of later adaptation. The higher the IQ, the closer the child will approach normal adaptation. Two independent studies (DeMyer et al., 1973; Rutter & Lockyer, 1967) demonstrated that an IQ below 40 is invariably predictive of poor outcome; conversely, an IQ above 60 or greatly increases the chances of educational progress and social adjustment.

The isolated abilities shown by autistic children often mislead us to overestimate their cognitive potential and underestimate their cognitive impairment. These so-called "splinter skills" prompted Kanner in his early writing to attribute "good cognitive potentialities" to these children. These abilities, which differentiate the autistic child from the child who is simply retarded, include motor and spatial skills, rote memory, and hyperlexia (Cobrinik, 1974; DeMyer et al., 1981; Rimland, 1964; Whitehouse & Harris, 1984). For many years, the assumption prevailed that these scattered skills gave glimpses of the child's "true" intelligence, which was masked by withdrawal and negativism. This led to the further assumption that the child's normal intelligence would emerge fully blown with removal of the emotional barriers.

The research already noted fails to support these assumptions of good cognitive potential in most autistic children. Even though autistic behaviors may diminish somewhat as the child grows older, the inferred potentialities are seldom realized. The isolated skills rarely merge into any adaptive intelligence that enables the child to understand and cope flexibly with the world. Most autistic individuals, then, maintain lifelong cognitive impairment. The specific defect underlying this impairment remains the subject of speculation, but intensive scientific effort, in the form of theory development and research, continues in an attempt to better understand what the defect is and how it is caused (Morgan, 1984, in press; Rutter, 1983).

Autism as a Biogenic Disorder

The psychogenic theory of autism—that is, the hypothesis indicting psychosocial variables as primary causes of autism—appears to be suffering a slow and painful death. However, just when the theory seems to be laboring for its last breath, someone attempts to resusitate it. No less a behaviorist scientist than the Nobel laureate Niko Tinbergen has recently emerged as an advocate of psychogenic theory (Tinbergen & Tinbergen, 1983). Surprisingly though, he presents highly speculative, anecdotal-based arguments reminiscent of those proposed by Bettelheim (1967) almost 20 years ago in his book *The Empty Fortress* (which Kanner [1969] referred to as the "empty book").

The primary reason for the demise of psychogenic theories of autism can be simply stated: There is little, if any, evidence to support such theories. In view of the evidence (or lack thereof), one wonders how the theories have survived as long as they have. Although no clear and consistent cause of autism has been determined, the inescapable inference to be

drawn from numerous studies is that the disorder is more clearly related to biogenic than psychogenic factors. Within the scope of this article, one cannot begin to review the research that bears on this issue; such a review would fill several volumes. Nevertheless, a summary of some of the major lines of evidence will be presented.

First is the question of whether parents of autistic children show special psychological characteristics that may be pathogenic for autism. Kanner (1943, 1949) and other writers (e.g., Eisenberg, 1957) argued that these parents are indeed a very special group in intelligence and personality. The classic "parent-of-an-autistic-child" that emerged from the literature was a highly intelligent, aloof, cold superachiever of high socioeconomic status. More recent, better controlled research casts doubt on this stereotype and suggests that it was based on biased samples. In a comprehensive study, Schopler, Andrews, and Strupp (1979) found no significant class differences in families of 522 autistic children evaluated at the University of North Carolina at Chapel Hill. In a review of research on family factors in autism, McAdoo and DeMyer (1977) concluded that parents of autistic children, in comparison to parents of children with other behavior disorders or handicaps, generally exhibit no deviant personality traits such as obsessiveness, coldness, or social anxiety, and no particular deficits in acceptance, nurturance, warmth, feeding, and general stimulation of their infants. A recent, well-conducted study by Koegel, Schriebman, O'Neill, and Burke (1983) further supported this conclusion by demonstrating that families of autistic children do not differ from "normal" families in terms of parental MMPI profile, marital happiness, family interactions, and parental stress. In view of the absence of research findings to support the psychogenic position, the burden of proof still rests squarely on the shoulders of the psychogenic diehards.

While there exists little evidence to support psychosocial causation of autism, we can point to clear and consistent findings that bolster the biogenic position. Because autism appears to emerge during early infancy, it is reasonable to suspect a genetic component. Indeed, twin studies have demonstrated a substantial genetic predisposition toward autism (Folstein & Rutter, 1977; Spence, 1976). Identical twins show a much higher concordance rate for autism than do fraternal twins. We cannot conclude, however, that the primary cause of autism resides in a single gene (as in phenylketonuria) or chromosome (as in Downs Syndrome), but rather that genetic factors appear to predispose some children toward developing the disorder.

Other research has demonstrated that autism can arise from a number of diverse neuropathological conditions, which include phenylketonuria, congenital rubella, tuberous sclerosis, lead intoxication, congenital syphilis, and Fragile-X Syndrome (Brown et al., 1982; Darby, 1976; Piggott, 1979; Rutter, 1979). Recent studies (e.g., Jones & Prior, 1985) report more signs of neurological dysfunction in autistic children than were noted earlier. These dysfunctions often emerge more clearly as the children grow older, even in those children who originally showed no such problems (Rutter, 1970; Wing, 1976). For example, the number of autistic children with abnormal EEGs is significantly higher than once suspected, and about one fourth or more exhibit convulsive disorders by the time they become adolescents and adults (Rutter, 1970).

The most plausible conclusion that we can draw from the available evidence is that autism is the behavioral end-product of an underlying organic defect (or combination of defects) that may arise in different ways through a variety of possible causal agents. The underlying defect or damage not only affects cognitive functioning but also emotional and affective perception and responsiveness (Rutter, 1983; Morgan, 1981, in press). By accepting the conclusion that the autistic child has an organic disorder, we do not deny that the disorder can be aggravated or improved to some extent by social and psychological influences. We are only rejecting the idea that the disorder is *caused* by such influences.

Intervention and Treatment

Despite claims made by more ardent advocates of certain treatments, there is no cure for autism. Some interventions, however, appear to help more than others. The most effective treatment programs are those that are started early and pervade the child's total life. Such programs require early diagnosis of autism, early counseling of parents, strong parental involvement in the child's treatment, and well-structured, individualized special education. For teaching the young autistic child speech, social, and self-help skills, application of behavior modification principles has been effective and appears to enhance adaptive functioning (Lovaas, Koegel, Simmons, & Long, 1973; Schriebman, Charlop, & Britten, 1983). Autistic children who respond best to behavioral treatment programs generally have parents who are willing to assume the role of primary therapists. Such treatment is much more effective when initiated early, and when the parents are committed to placing demands on the child and carefully managing behavioral contingencies.

Along with early intervention and parental involvement, special education has been shown to play an essential role in helping the autistic child to adapt to the world (Rutter & Bartak, 1973). Many communities now have special education programs designed to meet the needs of children with autism and related disorders. Such programs focus on the de-

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velopment of speech and cognitive skills, as well as social and adaptive skills. Special education efforts are most productive when integrated within broad community-based treatment programs. The TEACCH (Treatment and Education of Autistic and related Communications handicapped CHildren) programs in North Carolina represent a community approach that provides comprehensive educational and treatment services to autistic individuals and their parents (Reichler & Schopler, 1976). Unfortunately, most communities fall short of offering sufficient services of this kind.

An important, but often overlooked, aspect of intervention concerns the impact of the autistic child on parents and family members. For many years, the focus was on the influence of the family, particularly the parents, in the development of autism. With research now pointing overwhelmingly to organic causation, attention has gradually shifted to the special problems that an autistic individual creates within the family system. The National Society for Autistic Children and affiliated local chapters have served for some time as a source of support and information for parents and family. Professionals are now recognizing the special needs of the family, and are directing more effort toward research on family issues and development of appropriate services. In fact, a recent book, *The Effects of Autism on the Family* (Schopler & Mesibov, 1984), deals exclusively with this topic.

Another recent development in intervention has centered on the special needs of the autistic individual who has entered adolescence and adulthood (Schopler & Mesibov, 1983). Of special concern is vocational training and placement as well as provision of adequate adult residences, such as community group homes, as alternatives to institutional placement.

Since most evidence points to physical causation in autism, there have been increased attempts to find an effective biochemical treatment. Although a number of drugs have been tried, none have been successful in eliminating the basic symptoms of autism. Some have been useful (e.g., Haldol, Flenfluramine) in partially controlling associated problems, such as hyperactivity, attention problems, sterotypic behavior, and sleep disturbances (August, Raz, & Baird, 1985; Campbell, Geller, & Cohen, 1977; Campbell, 1978). Rather than serving as a primary treatment, such drugs are generally used as adjuncts to behavioral and educational interventions.

A controversial form of biochemical treatment that has received a great deal of publicity is so-called megavitamin therapy. Although improvement in behavior of some autistic children has been reported with high doses of single or multiple vitamins, the results are inconclusive, and additional studies are needed to establish the effectiveness of such treatment (Rimland, Callaway, & Dreyfus, 1978). Because of sometimes misleading publicity, parents tend to initially view special diets and vitamin therapies as panaceas, but later are disappointed with overall results.

Traditional psychoanalytic and "play therapy" approaches have failed in the treatment of autism (Rutter & Bartak, 1973; Schriebman, Charlop, & Britten, 1983). Aside from being time-consuming and often expensive, such approaches show no correlation with later outcome.

Long-Term Adjustment of Autistic Individuals

The question that eventually enters the minds of most persons interested in autistic children is: What happens to them when they grow up? The only basis for answers to this question is the available information we have on autistic individuals who have already reached adolescence and adulthood. From such data, we have determined those variables that are associated with long-term improvement and adjustment. The conclusions that we draw from such data, however, must be tentative and subject to revision; many of the individuals studied, especially those who are now adults, did not have the benefit of intensive early treatment or special education programs now available to autistic children in many communities.

The current outlook for autistic children as adults is generally poor. In a recent review of all follow-up studies on autistic children, Lotter (1978) reported that only 5-17% eventually achieved "good outcomes" as adolescents or adults; that is, their social life was near normal, and school or work performance was satisfactory. On the other hand, 61-74% had "very poor outcomes" and were incapable of leading independent lives.

As noted previously, two of the strongest predictors of positive outcome are early communicative speech and relatively high measured intelligence (Kanner, Rodriquez, & Ashenden, 1972; Lotter, 1978). Other factors related to later adjustment include neurological factors, severity of early symptoms, play behavior, early intervention, parental commitment to treatment, and special education. Seizures and other clear signs of neurological dysfunction or damage are correlated with severity of retardation and long-term impairment (Lotter, 1978). The severity of early symptoms also relates to later adjustment; the more pronounced the autistic syndrome, the poorer the response to treatment and educational programs (DeMyer et al., 1973). The young autistic child's play behavior also gives clues about prognosis; if the child plays appropriately with toys before age 5, this is a positive sign (Brown, 1960). Further, if the parents are willing to commit themselves to a systematic behavioral program for the child at an early age, then chances of later adaptation are increased (Lovaas et al., 1973; Schriebman & Koegel,

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1975). Finally, participation in a well-structured special education program where the child receives individual attention improves the long-term outlook (R· · & Bartak, 1973).

We should not view these factors as final answers to the questions of long-term prognosis in autistic children, nor should we regard them as infallible predictors of success or failure. We must keep in mind that most of the intervention programs, such as TEACCH, have been developed only in recent years. This is especially true of the therapeutic and educational programs that intervene early in the lives of young autistic children. We should remember, too, that a number of research projects, ranging from behavioral to cognitive to biochemical, are currently being conducted. This research should yield answers that will aid us in developing more effective preventive and treatment programs—programs that will cast a more optimistic light on the prospects of the autistic child.

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